

*A MIXED METHODS STUDY OF REACH  
ADVOCACY: A RECOVERY-ORIENTED  
ADVOCACY SERVICE BASED IN NORTH  
LANARKSHIRE*

*RIGHTS BASED  
ADVOCACY AS  
INTERVENTION*

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# *RIGHTS BASED ADVOCACY AS INTERVENTION:*

## *A MIXED METHODS STUDY OF REACH ADVOCACY:*

### *A RECOVERY-ORIENTED ADVOCACY SERVICE BASED IN NORTH LANARKSHIRE*

This research study evaluates an independent rights-based advocacy service Reach Advocacy. This study is funded by the Glasgow Council on Alcohol.

The researchers gratefully acknowledge the help and support of Turning Point Scotland for help in securing funding from GCA, as part of Elevate, Glasgow.

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### **Aim**

The overarching aim of this evaluation of an independent advocacy training service provider, and independent rights-based advocacy service was to examine the impact of RAPA<sup>1</sup> training, document the QoL of candidates and clients using the advocacy service in the context of recovery.

### **Methods**

Using mixed methods to gather quantitative and qualitative data we evaluate Reach Advocacy (RA) service, an independent rights-based advocacy service in the context of recovery from the perspectives of Trainers, RA Volunteers, RAPA Candidates, and Clients (pre-Candidates) attending RA.

Fieldwork took place in and around the premises of Reach Advocacy based in Coatbridge, and service providers within North and South Lanarkshire and Glasgow.

RA client perspectives of rights-based advocacy were documented using semi structured interviews.

In addition, the WHOQoL-100<sup>2</sup> questionnaire was used at initial contact and after a period of ten months after initial contact, measuring QoL in the context of recovery.

RAPA candidate therapeutic attitudes to working with vulnerable client groups were documented pre and post RAPA training using an adapted AAPPQ<sup>3</sup>.

### **Findings**

1 An inclusive rights-based approach to advocacy in the context of recovery is innovative and markedly different from existing needs and issues-based service provision for problem AOD<sup>4</sup> users and dual diagnosed individuals.

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<sup>1</sup> Reach Advocacy Practice Award

<sup>2</sup> World Health Organisations quality of life 100 item questionnaire

<sup>3</sup> Alcohol and Alcohol problems perception questionnaire

<sup>4</sup> Alcohol and other drugs

2 Candidates successfully completing The SCQF level 7 RAPA document higher levels of therapeutic commitment using the adapted AAPPQ which indicates that the RA services staffed by individuals with lived experience can and do create education opportunities in the context of recovery using innovative and national standardised vocational education.

3 Service provision underpinned by Human Rights and lived experience of individuals in recovery, impact positively on quality of life (QoL) across the social determinants of health documented using the WHOQoL-100. We evaluated the suitability of using the WHO QoL questionnaire on individuals in recovery and discovered that the longer the candidates and pre-candidates (RA clients) were in recovery, broadly, the higher the scores in each of the 6 domains in the WHOQoL-100. This has allowed us to introduce a new term into the recovery lexicon, that of 'recovery oriented QoL'. The longer a candidate is in recovery, the higher QoL mean scores. Conversely, clients attending RA, who have not maintained or achieved long term recovery have low QoL mean scores.

## **Recommendations**

A rights-based person-centred approach to problem AOD use and dual diagnosed individuals requires a new way to understand how to commission services. This means a move from needs-based approaches that focus on one issue such as drug and alcohol consumption, mental health, treatment compliance, or on housing that create eligibility criteria, which can also be perceived as barriers to recovery.

A rights-based approach to problematic AOD use and dual diagnosis services requires universal services and commissioners to have as their starting point, the understanding that vulnerable and marginalised AOD users and dual diagnosed individuals present with complex and concurrent issues whilst experiencing the effects of marginalisation and discrimination.

The Social Security Bill (Scotland) 2018 describes newly devolved social security powers. Amendment 35 states that any Advocacy Worker working with vulnerable individuals has to abide by the advocacy service standards within a nationally recognised quality assured advocacy award by the Scottish Qualifications Authority (SQA). The RAPA provided by Reach Advocacy fits this criterion. The advocacy training standards indicate that services providing training in Advocacy should have embedded quality assured processes. The RAPA has been quality assured and assessed by the SQA and fits these criteria.

The RAPA training is underpinned by a strong focus on Human Rights aligned to The Scottish Governments Scottish National Action Plan (SNAP) and (P.A.N.E.L) principles of *Participation, Accountability, Non-Discriminatory, Empowerment, Legality*.

We recommend that service purchasers and providers acknowledge that problematic AOD users, and dually diagnosed individuals are **rights bearers**, and existing services as **duty bearers** should fully embrace Rights Based Advocacy (RBA), not in a tokenistic manner, to access government funding, but at the forefront of service provision.



“...recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world...THIS UNIVERSAL DECLARATION OF HUMAN RIGHTS as a common standard of achievement for all peoples and all nations, to the end that every individual and every organ of society, keeping this Declaration constantly in mind, shall strive by teaching and education to promote respect for these rights and freedoms and by progressive measures, national and international, to secure their universal and effective recognition and observance”.

**Preamble, the United Nations Universal Declaration of Human Rights, 1948**



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## SECTION 1: OVERVIEW

This study utilises a mixed methodology to evaluate the rights-based advocacy service Reach Advocacy (RA). A quasi-experimental design was used to assess the influence of an SCQF level 7 Reach Advocacy Practice Award (RAPA) on candidates in recovery who work in front line services on their commitment to working with vulnerable individuals.

The alcohol problems perception questionnaire (AAPPQ) developed by Shaw, Cartwright, Spratley & Harwin, (1978) was adapted by McPhee et al., (2012) to evaluate the impact of the Reach Advocacy Practice Award (RAPA) on the therapeutic commitment of candidates who successfully completed the RA practice award (RAPA). The measurement of therapeutic commitment reflects a human rights-based approach to working with vulnerable, marginalised and stigmatised individuals with complex needs. In addition, the study investigates the suitability of using the WHO QoL-100 questionnaire<sup>5</sup> to understand the QoL of dual diagnosed clients (pre-candidates) in contact with RA within the context of recovery.

The research data included into this report was conducted between January and September 2018. The updated 2019 alcohol and drugs strategy 'Rights, Respect, Recovery' indicates that there is an interest in exploring rights-based services for individuals with complex needs in addition to traditional issues-based services, in particular services that seek to increase contact with stigmatised and vulnerable individuals in recovery from AOD<sup>6</sup> problems, and at great risk of drug related death (McPhee, Sheridan & O'Rawe, 2019).

The ethics application was submitted to UWS ethics committee in June 2017 and approved in August 2017. This report was funded by Glasgow Council on Alcohol to inform and further the Elevate<sup>7</sup> Glasgow Initiative of which The University of the West of Scotland is a signatory. There are 3 aims of the study:

1. To evaluate the impact of the rights-based Reach Advocacy practice award (RAPA) on the therapeutic commitment<sup>8</sup> of candidates who successfully completed the training.

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<sup>5</sup> The WHOQoL-100 is a one hundred item questionnaire designed by the World Health Organisation, measuring quality of life

<sup>6</sup> Alcohol and other drugs

<sup>7</sup> Elevate-Glasgow is an Employability Public Social Partnership for individuals in recovery from problematic drug &/or alcohol misuse which involves over 30 organisations.

<sup>8</sup> In this study therapeutic commitment, is understood as a commitment to a human rights-based approach (humanitarian commitment) to working with vulnerable, marginalised and stigmatised individuals with complex needs.

2. To explore the Quality of Life scores of candidates and pre-candidates in recovery attending the rights-based reach advocacy service (RBAS) at the beginning of contact and at completion of RAPA training or advocacy intervention.
3. To highlight gaps in current service provision<sup>9</sup> for vulnerable clients from service user and service provider perspectives.

## REACH ADVOCACY

Reach Advocacy (RA) a rights-based advocacy service started its journey in 2009 when two individuals Derek McCabe and Gerard (Jed) Brady met at a Hope and Recovery Conference in Scotland. They helped establish the Lanarkshire Recovery Consortium (LaRC) in 2010. These individuals with lived experience of recovery began developing what was to become the Reach Advocacy Practice Award (RAPA) seeking to educate and inform people with alcohol and other drugs (AOD) problems who also suffer mental ill health and to promote recovery in this context.

The RAPA is based on promoting understanding of human rights underpinned by the principles of Fairness, Respect, Equality, Dignity and Autonomy (FREDA) and the social determinants of health (Kirkemann & Martin, 2007; Care Quality Commission, 2014; NHS Scotland, 2016; UN, 2017).

RA was set up in March 2017 funded by Big Lottery Fund for three years to provide education in the form of vocational training. Year one was fully funded, and year 2 and 3 half funded. The level 7 SCQF Reach Advocacy Practice Award<sup>10</sup>, was developed primarily for people in recovery from problematic AOD use and mental ill health and other complex needs. RA developed the RAPA to help vulnerable individuals understand and enact their rights when dealing with government institutions, and social care services to redress the power imbalance between individuals and large institutions, promoting the right to health, and the social determinants of health. While mental ill health is a condition recognised by medicine, with rights underpinned by equality legislation, individuals with AOD problems, while recognised as suffering a recognised medical condition, problematic AOD users lack protection in law to access their rights to health.

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<sup>9</sup> Clients particularly those who are dual diagnosed, who require rights-based advocacy in the context of recovery often fail meet the criterion for help from several needs-based services, including treatment providers, social work, Housing, health, and in accessing welfare (benefits) DWP.

<sup>10</sup> The Scottish Credit Qualifications Framework (SCQF) Level 7 RAPA award is equivalent to an SVQ Level 3 qualification

RA are a rights-based advocacy service who recognise the rights of a highly stigmatised group (problem AOD users) and support these rights in achieving and maintaining recovery.

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#### DAY TO DAY ACTIVITY AT REACH ADVOCACY

There are 2 services that RA offer. Training in the RAPA, and a walk-in advocacy service based in Coatbridge, North Lanarkshire.

**RA Service 1:** Reach Advocacy provide training in the form of the RAPA, in rights-based advocacy, linked to recovery from AOD use, and mental ill health, advocate for vulnerable and marginalised individuals. RA offer the RAPA training to candidates who have been able to demonstrate maintenance of a stable recovery at stage 3. They determine this using a four-stage model of recovery. The four stages include: stage 1: pre-recovery; stage 2: recovery initiation; stage 3: recovery maintenance; stage 4: enhancement in quality of personal/ family life.

In addition, RA have made significant links with several agencies, including Barlinnie Prison, Veterans First, etc. to provide advocacy in the context of recovery from beyond the office space in Coatbridge.

**RA Service 2:** A walk in service available to all stigmatised, vulnerable and marginalised individuals from their local area (North/South Lanarkshire, and Glasgow) offering rights-based advocacy in accessing rights to health, education, welfare, housing, and the promotion of recovery.

Other activities, as an independent advocacy service funded for only 3 years by TBLF<sup>11</sup>, there is a significant amount of time devoted to seeking adequate funding to provide services.

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<sup>11</sup> The Big Lottery Fund

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## SETTING THE SCENE

In addition to complex health and social care needs, people who use, or have used, illegal drugs face additional challenges that impact on their human rights. Despite the United Nations (UN) Declaration on Human Rights in 1948 signifying that rights are universal and available to all, people who use drugs had these rights challenged when the UN ratified the 1961 UN Convention on Narcotic drugs, which criminalised the possession, sale and manufacture of opium, cocaine and cannabis. Further drugs were added to the list of controlled substances in the UN Convention on Psychotropic Drugs, 1971. The 1971 Convention also linked the use of drugs to mental ill health, medicalising, and further stigmatising, in addition to criminalising and eroding the rights of users of prohibited drugs and creating future potential for discrimination of people who use disapproved (non-medical) drugs.

In 1971, the United Kingdom (UK) criminalised the possession of controlled drugs using an A-C classification system within the confines of the Misuse of Drugs Act (1971). Criminalising drug possession further eroded the rights of people who use drugs prohibited by law.

The United Kingdom Human Rights Act 1998 sets out the fundamental rights and freedoms that everyone in the UK is entitled to. It incorporates the rights set out in the European Convention on Human Rights (ECHR) into domestic British law.

## SECTION 2: INTRODUCTION

The preamble from the 1948 UN Declaration on Human Rights indicates that the equal rights and dignity of all human beings in the world is a common standard of achievement for all people, and that all should strive by teaching and education to promote respect for these rights and freedoms and secure their effective recognition and observance. However, the rights of AOD users have been systematically eroded over time. AOD users are criminalised, stigmatised individuals and are vulnerable insofar as the common rights enjoyed by most people in Scotland, are routinely denied to problem AOD users. This occurs in numerous ways and are documented in this evaluation.

### ADDRESSING COMPLEX NEEDS

In defining what can be understood as vulnerable in the context of recovery, this section explores definitions of AOD problems and how this is related to mental ill health. We then briefly introduce the impact of stigma, discrimination, and deprivation in the context of vulnerability and complex needs and describe what is understood as the social determinants of health. Next, we discuss the main differences between needs-based services and rights-based services. Then we introduce the concept of advocacy from several perspectives. Finally, we introduce a discussion on defining quality of life, in the context of recovery.

### DEFINING VULNERABILITY

The etymology of the term vulnerable used as an adjective stem from the Latin verb '*vulnerare*' meaning to wound, hurt, injure or maim. To define a person as vulnerable there is a statutory term 'vulnerable adult' used by Social Workers describing people over the age of 18, to whom the state and various agencies and people who work within them have specific safeguarding responsibilities such as: Living in residential or sheltered accommodation; in receipt of certain types of health and social care; receiving certain types of welfare support and some persons detained in lawful custody.

Ruof, (2004) describes the following groups as vulnerable including problem users of alcohol and other drugs, people with mental ill health, people recently released from prison, and individuals in early stages of recovery from AOD use and mental ill health. These individuals have complex problems, and vulnerable to marginalisation, stigma and discrimination. In addition, deprivation and poverty all exacerbate many of these complex problems, and further increase the risk of suicide and early death. Statistics from ISD published in 2018 indicate that there were 934 drug

related deaths (DRD), 1,120 alcohol related deaths (ARD) and 728 Suicides in Scotland in 2017 (ISD 2018; NRS 2018; McPhee, Sheridan & O’Rawe, 2019).

## **Defining addiction**

The Diagnostic and Statistical Manual has defined addiction or dependence (the terms are often used interchangeably) from a medical perspective as:

*“...a chronic relapsing condition, characterised by chaotic drug seeking behaviour, and continued use, despite adverse consequences” (DSM-V, 2013).*

The UNODC describe drug dependence as a health disorder stating that:

*“Drug dependence is considered a multifactorial health disorder that often follows the course of a relapsing and remitting chronic disease. Unfortunately, in many societies drug dependence is still not recognized as a health problem and many people suffering from it are stigmatized and have no access to treatment and rehabilitation...” (UNODC, 2008: p1).*

There is much controversy regarding whether addiction is an illness which is chronic and relapsing, or a temporary life style problem. However problematic AOD is defined, there is no doubt that problematic dependent users of AOD are stigmatised.

Bauld et al., (2010) provide a profile of a problem drug user which depicts the many barriers and challenges they must overcome:

*“Overall, they are a marginalised group, many of whom (although not all) have experienced disadvantage from an early age” (Bauld et al: p.1).*

Problems with housing and homelessness are commonly reported in studies accessing drug-using populations (Kemp et al., 2006) as are low levels of educational attainment (Puigdollers et al., 2004; Luck et al., 2004). The literature documents a number of concurrent physical health problems, particularly among long-term drug users (Hser et al., 2004; SDF 2007), including higher rates of hepatitis C, HIV/AIDS and physical impairments that can affect problem AOD user’s ability to complete everyday tasks and ability to maintain employment (Neale, 2001; Kemp & Neale, 2005; March et al., 2006; Payne-James et al., 2005). The prevalence of a range of mental health problems amongst problem AOD users is also well documented (Graham et al., 2001, Johnson et al., 2002).

## Dual diagnosis

Lehman et al., (1989) classified individuals with dual diagnosis using clinical criteria and suggested 4 classifications (1) primary mental illness and substance misuse, whereby the symptoms of mental illness lead to drug use, (2) substance misuse with psychiatric progression, where the use of substances or withdrawal from them can cause mental ill health, (3) dual primary disorder, where the substance use and the mental illness are initially unrelated and can interact and worsen both conditions, (4) common etiological groups, in which common underlying factors (homelessness as a risk factor for both depression and misuse of drugs) and may predispose individuals to both conditions (Lehman, et al. 1989; Williams 2002).

A review of the dual diagnosis literature indicates that people with drug problems and who suffer from mental ill health have increased likelihood of self-harm and violence; poor physical health (including HIV infection); relapse and rehospitalisation; medication non-compliance; family problems, homelessness, legal issues and offending (Priester et al., 2015).

Globally, the UN has recognised the complex needs facing people with co-occurring mental illness and substance use disorders (Dual diagnosis). Many of these complex needs manifest in the difficulty such individuals report in accessing welfare and understanding their rights to health, housing, benefits, education and employment. These areas overlap with social determinants underpinning the right to health and to participate in society on an equal footing (The Scottish Executive, 2003; UN High Commissioners Report 2016; NHS Scotland, 2016).

A review of the available data reveals that over 50% of people seeking help with their mental health are also experiencing problems with AOD (ISD 2018). As a result of how services are set up, such individuals are caught between addiction and mental health services who have very different understandings and funding mechanisms to determine what needs are considered as a priority.

The Scottish Executive published a report titled 'Mind the gaps, meeting the needs of people with co-occurring substance misuse and mental health problems' (Scottish Executive, 2003). In this report, dual diagnosed populations are described as having co-occurring mental health and substance misuse problems and often occupy the margins of our society. While some can benefit from help and support of many types, there are shortcomings and gaps in the help that is available. In summary the evidence indicates that:

- Up to 3 in 4 drug using clients have been reported as having mental health problems;
- Up to 1 in 2 patients with alcohol problems may also have a mental health problem;
- Up to 2 in 5 people with mental health problems may have a drug and/or alcohol Problems.

The report indicates that people who experience co-occurring substance misuse and mental health problems also experience other complex social problems, such as unemployment, homelessness, violence and childhood trauma which manifest over long periods of time. The 2003 report also indicated that mental health services focus their service provision narrowly in medicalising mental health problems. Staff were often unwilling to work with individuals with complex needs, and there was a significant lack of communication between agencies, particularly between mental health services, and AOD treatment providers (The Scottish Executive, 2003).

Ugbja (2012) in a review of Epidemiological Journals on Mental Health identifies clear links between poverty and chronic health problems. Establishing explanations from a theoretical perspective suggests that deprivation and poverty are correlated with reported emotional distress, (Patel, 1995) and reported diagnoses of mental ill health being highest among the most deprived people (Patel et al., 2003). Indeed, for Ugbja poverty is a gateway to mental ill health, insofar as poverty and inequality increases so does the reported incidences of homelessness, drug dependence, alcohol problems and mental ill health (Ugbja, 2012:2).

## **Deprivation**

There is significant evidence that social conditions associated with deprivation facilitate initial drug experimentation and use, encourage a progression into problematic drug use, and exacerbate the risks for negative outcomes including DRD (ACMD, 1998). While caution should be placed on drawing firm conclusions on the links between deprivation and problematic drug use, as problematic drug use occurs across different socio-economic conditions, deprivation can significantly increase the risk of DRD (McPhee, et al., 2018). Exploring the links between deprivation and problematic drug misuse, the ACMD notes that:

*‘Whatever the objective criteria which are employed to measure deprivation it is important to realise that what we are talking about here is a condition which at the same time will often exist as a potent, corrosive, subjective and personal experience. The mix of feelings are likely to include worthlessness and a sense of failure, powerless and the feeling of not being in control, alienation and apathy and loss of any role as stakeholder, the sense of lacking any hope of a personal way out or up and of there being no better future in sight for one’s children. Deprivation is a psychological burden’ (ACMD, 1998: 100).*

The ACMD in 1998 recognised that deprivation is subtly connected to increased risk factors such as progression from recreational use to problematic use, the intravenous injection of drugs, health and social complications related to injecting, and being caught within the criminal justice



system. Being fined for possession, or jailed for possession with intent to supply, within the Misuse of Drugs Act (1971), create intractable relationships between drug taking, criminality, and poverty (Hammersley, 2008). While in recovery, the stigma associated with the use of illegal drugs further impacts on perceived and stigma and discrimination reported by service users (McPhee et al., 2013).

### **AOD service provision in Scotland**

Responsibility for treatment, support and other service provision is devolved to Scotland's 30 Alcohol and Drug Partnerships (ADPs) (formerly Alcohol and Drug Action Teams) to commission treatment services to address drug problems in their area (Audit Scotland, 2009; SPICe briefing paper 2017).

In 2016 the Scottish Government cut funding to local services by 22% which was maintained in 2017-18 (SPICe, 2018). The published figures for funding for NHS and Alcohol and Drug Partnerships (ADPs) in Scotland indicate a 20% cut from £69.2m in 2015-2106 to £53.8m in 2016-2017 (Davies, 2017:35).

The impact of austerity made resource allocation to services difficult for national governments, local authorities and ADP's. In a review of future public service delivery, commonly known as The Christie Commission it is stated that:

*'We must prioritise expenditure on public services which prevent negative outcomes from arising' (Scottish Government, 2011: vi)*

However, the Christie Commission was short on specifics of what these negative outcomes might be and mentioned the Scottish drug situation only fleetingly predicting that:

*'The pressure on budgets is intense and public spending is not expected to return to 2010 levels in real terms for 16 years' (Scottish Government, 2011: viii)*

Cuts to services that provide wide-ranging treatments and support to drug users in areas where drug problems are exacerbated by multiple deprivation and poverty, are exactly those areas where the cuts to services impact upon the most vulnerable and marginalised individuals with complex needs.

## The drug policy context

The Misuse of Drugs Act 1971 is the primary legislation for the United Kingdom and came fully into effect in 1973. The Act introduced the term 'controlled drugs' replacing the previously used term 'dangerous drugs'.

Since the inception of the Scottish Parliament in 1999, three Scottish drug strategies have been implemented. The first being the Scottish Executive's, Tackling Drugs in Scotland: Action in Partnership (1999). This strategy had four pillars similar in approach to the UK government drug policy document Tackling Drugs Together to Build a Better Britain (1998).

In the early 2000's with increasing drug related deaths linked to methadone, a focus on abstinence recovery was considered to be the answer to address the risk factors associated with problematic drug use (Ashton, 2008). At this time there was growing movement supporting abstinence recovery as a treatment goal within treatment services (Duke et al., 2013). In 2006, researchers claimed that under 10% of males and females were achieving abstinence after 33 months of treatment. The findings indicated that almost 6 in 10 wanted to be abstinent while less than one in ten achieved it (McKeganey et al., 2006).

The formation of Alcohol and Drug Partnerships in the mid-2000s brought together a range of statutory bodies to address problematic drug and alcohol use. This change of strategic focus was exemplified in the second drug strategy in Scotland. The Scottish Government published, in May 2008, "The Road to Recovery". At its launch they defined recovery as:

*'...a process through which an individual is enabled to move on from their problem drug use, towards a drug-free life as an active and contributing member of society' (Scottish Government, 2008: 23).*

The Road to Recovery (Scottish Government, 2008) set out a new drug treatment strategy in Scotland that emphasised a drug free lifestyle as its central tenet. In 2018, the recent alcohol and drug strategy, 'Rights, Respect and Recovery (2018) indicates that the Scottish Government remain committed to problem AOD users achieving and maintaining abstinence recovery.

A battle between harm reduction and abstinence-oriented definitions of recovery has emerged in the UK in general, and in Scotland in Particular:

*'In the last 20 years, the recovery movement in alcohol and other drugs has emerged as a major influence on alcohol and drug policy and practice in the UK, US and Australia' (Best et al., 2017: 1)*

This comment highlights the ideological shift from harm reduction-based recovery toward abstinence-based recovery (Hammersley & Dalgarno 2012).

## **Recovery**

Because it can be applied to many different contexts, the meaning of recovery can be ambiguous and confusing. The term “recovery” is used in connection with healing from mental illness, and commonly associated with overcoming addiction to alcohol and other drugs. In this context, underpinned by popular descriptions emerging from 12 step alcohol groups, recovery is generally thought of as becoming abstinent from problematic AOD use.

The process of recovering from AOD use is recognised as taking considerable time (5-7 years), and is reliant on not just treatment provision, but on what has become known as ‘recovery capital’ (See Best et al., 2010). Recovery capital is best described as those resources internal and external that foster recovery.

### **Recovery capital**

The best predictor of the likelihood of sustained recovery is the extent of ‘recovery capital’ or the personal and psychological resources a person has, the social supports that are available to them and the basic foundations of life quality, i.e. a safe place to live, meaningful activities and a role in their community (however this is defined).

Recovery capital refers to the measurable and comparable internal and external resources that can be mobilised to initiate and sustain the resolution of severe alcohol and other drug problems (Granfield & Cloud, 1999). Internal assets can be thought of as personal recovery capital and external assets can be thought of in terms of family and community recovery capital (White & Cloud, 2008). Thus, recovery capital will change over time and is amenable to measurement as a mechanism for assessing appropriate interventions<sup>12</sup>.

Barriers to recovery include psychological problems (mental illnesses and the absence of strengths, such as self-esteem and self-efficacy), significant physical morbidities (including blood borne viruses), social isolation and ongoing chaotic substance use (Best et al., 2010, p.8).

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<sup>12</sup> The measurement of recovery capital ignores environment and structural factors, such as deprivation and poverty.

## **Stages of recovery**

There is scientific literature positing stage theories of addiction recovery (DeLeon, 1996, 2007; Frykholm, 1985; Klingemann, 1991; Prochaska et al., 1992; Shaffer & Jones, 1989; Waldorf, 1983; Waldorf et al., 1991). These studies suggest that:

- Addiction recovery, like the active process of addiction, is often characterised by recognisable stages and milestones;
- The movement through the stages of recovery is a time-dependent process;
- Within each stage of recovery are developmental tasks, skills to be mastered, certain perspectives to be developed, and certain issues to be addressed before movement to the next stage can occur.

Reach Advocacy utilise a four-stage model of recovery, and report that individuals who are able to reach stage three (recovery maintenance), may be suitable to embark upon the RAPA. The four stages include: stage 1: pre-recovery, stage 2: recovery initiation, stage 3: recovery maintenance, stage 4: enhancement in quality of personal/ family life.

However, even after recovery is established, AOD users and dual diagnosed individuals may still experience stigma.

## **Stigma**

The UKDPC report 'Getting Serious about Stigma: The problem with stigmatising drug users' (2010) note in their overview that:

- Stigma experienced by drug dependent users and their families often delays people seeking help.
- They fear that once they do, they will be stuck with the label 'hopeless addict' for life.
- Professional attitudes all too often reinforce stigma and lower expectations of recovery.
- Stigma puts barriers in the way of recovery and reintegration, for example by making it difficult to find employment.

Being labelled or considering oneself to be stigmatised and at risk of discrimination, accessing rights to health can be extremely difficult for current and former problem AOD users, and dual diagnosed individuals.

## **Deviance and non-conformity in the context of recovery**

Howard Becker (1963) in his classic work 'Outsiders' states that deviance or non-conformity is not a quality of the act, but rather a consequence of the application by others of rules and sanctions. As a result of this line of enquiry Becker questions who and how deviance becomes labelled. Becker asks the crucial question "What or who within a society determines deviance?"

Deviance does not refer solely to the behaviour of the individual but concerns the activities of groups as well. For example, heroin users represent in sociological terms a 'deviant life style or choice'. These drug users are perceived to 'live' on the margins of wider society. Through a process of constructing stereotypes, individuals who do not conform to expected social norms can become marginalised. Deviation from the 'norm' becomes defined as abnormal or psychopathological (Campbell, 1981; Glassner & Loughlin, 1987).

Historical, psychological and medical concepts of addiction have all influenced public opinion, decision makers, and service providers. Such discourse can play an important role in revealing the political implications of addiction. Definitions can, when accurately constructed, give a clear insight into the nature and causes of uncontrolled AOD use. Definitions are also a convenient means for labelling those deserving of access to services or punishment or disapproval. Definitions of social problems actually determine policy responses. They translate directly into how resources are allocated. Descriptions become labels which can pigeonhole individuals in negative ways.

## **How rights are conceptualised**

Human rights gained their first modern expression in the Universal Declaration of Human Rights (1948), which is described as 'a common standard of achievements for all peoples and all nations' in the preamble.

The right to health is a fundamental part of our human rights and of our understanding of a life in dignity. The right to the enjoyment of the highest attainable standard of physical and mental health is not new. Internationally, it was first articulated in the 1946 Constitution of the World Health Organization (WHO), whose preamble defines health as:

*"...a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (Grad, 2002).*

The preamble further states that:

*“the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition” (ibid).*

The 1948 Universal Declaration of Human Rights mentions health as part of the right to an adequate standard of living (see article 25 in appendix 5). The right to health was again recognised as a human right in the 1966 International Covenant on Economic, Social and Cultural Rights.

Since then, other international Human Rights Treaties have recognised or referred to the right to health or to elements of it, such as the right to medical care. However, rights are defined beyond access to medical care. The WHO note that in relation to health:

*“...Human rights are interdependent, indivisible and interrelated. This means that violating the right to health may often impair the enjoyment of other human rights, such as the rights to education or work, and vice versa. The importance given to the “underlying determinants of health”, that is, the factors and conditions which protect and promote the right to health beyond health services, goods and facilities, shows that the right to health is dependent on, and contributes to, the realization of many other human rights. These include the rights to food, to water, to an adequate standard of living, to adequate housing, to freedom from discrimination, to privacy, to access to information, to participation...” (OHCHR/WHO, 2008: p.6).*

The commonly reported challenges and barriers experience by AOD/DD populations indicate clearly that they do not enjoy the rights afforded routinely to non-stigmatised individuals and groups. It is also clear that AOD and DD individuals do not enjoy the same ‘rights’ to health as others.

### **The right to health: Social determinants of health**

In August 2008 in Geneva, the World Health Organisation Commission on the social determinants of health reported their findings of a three-year investigation to the Director General of the World Health Organisation. They noted that a child born in a Glasgow area characterised by

deprivation (see the SIMD<sup>13</sup>) can expect a life 28 years shorter than another living only 13 kilometres away in the suburbs. They stressed that genetics, or biology does not explain any of this. Instead, the differences between - and within – communities result from the social environment where people are born, live, grow, work and age. The Commission suggest that inequality is complex resulting from:

*"(The) toxic combination of bad policies, economics, and politics is, in large measure responsible for the fact that a majority of people in the world do not enjoy the good health that is biologically possible...Social injustice is killing people on a grand scale" (WHO, CSDH, Marmont et al., 2008).*

Inequalities in health outcomes are apparent as large numbers of problem users of AOD in Scotland are most often individuals who reside in postcode areas categorised as the most deprived in Scotland.

Chapman in 2010, discussed a rights-based approach to health focussing on three topics: 1) the social determinants of health and the underlying determinants of health; 2) health inequalities and inequities; and 3) power, money, and resources. Chapman argues that:

*"...the right to health requires greater attention to the social determinants of health, health inequalities, and power dynamics than these topics have received to date..." (Chapman, 2010 p. 1)*

The International Covenant on Economic, Social and Cultural Rights in 1976 states that all people have a right to the highest attainable standard of physical and mental health. This has been recognised formally in the UK since 1976 when the Government approved the International Covenant on Economic, Social and Cultural Rights. The Scottish Parliament note their commitment to Human Rights are underpinned by social determinant of health stating that rights, freedoms and personal integrity can be part of a human rights approach to service provision noting that:

*"...Civil and political (Human Rights) rights relate to the 'personal integrity', sometimes termed 'freedom' of an individual; for example, the right to life, right to liberty, and free speech...Economic, social and cultural (ICESCR) rights relate to the satisfaction of human needs and are generally associated with*

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<sup>13</sup> The Scottish Index of Multiple Deprivation: <http://simd.scot/2016/#/simd2016/BTTTFTT/9/-4.0000/55.9000/>

*the equality of individuals; for example, the right to health, the right to food, and the right to adequate housing...” (Shields, 2017, pp. 7-8)*

NHS Health Scotland (2016) stress a commitment and recognition of Human Rights and the Right to Health noting that:

*“...Human Rights belong to everyone, everywhere, throughout our lives, from birth until death. They are the basic rights we all have because we are human, regardless of who we are, where we live or what we do. They cover many aspects of everyday life, ranging from the rights to an adequate standard of living (including food and housing), education and health, freedom of thought, religion and expression” (NHS Scotland, 2016).*

The WHO (2017) Human Rights and Health document that the right to health, as with other rights, includes both freedoms and entitlements:

- **Freedoms** include the right to control one’s health and body (for example, sexual and reproductive rights) and to be free from interference (for example, free from torture and non-consensual medical treatment, or being denied access to treatment for non-compliance, with abstinence focused treatment protocols).
- **Entitlements** include the right to a system of health protection that gives everyone an equal opportunity to enjoy the highest attainable level of health.

It should be noted that rights are universal and inalienable as described in the 1948 UN Declaration, while a Nation State can pronounce entitlements to be privileges, which can be removed, or denied.

### **Rights to health in the context of recovery**

A rights-based approach to health conceptualises recipients of a service as ‘bearers of rights’, and to whom service providers can be defined as ‘duty bearers’. In this approach, rights to health can be defined as:

*“A human rights-based approach to health specifically aims at realizing the right to health and other health-related human rights. Health policy making and programming are to be guided by human rights standards and principles and aim at developing capacity of duty bearers to meet their obligations and empowering rights-holders to effectively claim their health right” (United Nations, 1986:5).*



From this perspective ‘rights bearers’ include individuals who have AOD problems and suffer concurrently mental ill health. The ‘duty bearers’ naturally include government, but also ADP<sup>14</sup>, and professions and agencies that provide services to those rights bearers. At present, many rights bearers are unaware of their rights, and potentially many duty holders remain uninformed about their responsibilities to rights bearers (clients and patients for example) and to whom they are accountable.

These understanding of rights however are often not accorded, or indeed recognised by service providers when providing services for AOD users. The report to the UN by Paul Hunt, the former Special Rapporteur on the right to health acknowledged that persons who use drugs are:

*“... a highly stigmatized and criminalized population whose experience of health-care is often one of humiliation, punishment and cruelty...In some cases the laws specifically single out the status of a drug user as a stand-alone basis for depriving someone of custody or other parental rights. Use of drug registries – where people who use drugs are identified and listed by police and health-care workers, and their civil rights curtailed – are violations of patient confidentiality (ibid) that lead to further ill-treatment by health providers” (Mendez, 2013:17).*

### **Needs based versus rights-based services**

The significant difference between rights based and a needs-based service is how they engage individuals with complex needs. A rights-based approach considers individual problems from a fundamental human rights perspective, underpinned by legislative frameworks, while needs based approaches frame issues and provides a service based on ‘needs based’ assessments.

Emerging primarily from a public health perspective, needs based assessments in relation to health are intended to inform commissioning and service planning and can be defined as a systematic method of identifying the unmet health and healthcare needs of a population and making changes to meet those unmet needs (Wright, et al., 1998). Such an approach allows government and ADP’s to target resources, and often involves working in partnership with other agencies, communities and service users.

The limitations of the more traditional approaches to rights-based services are described in the Danish Institute of Human Rights Based Approach to Advocacy, published in 2007, and highlight

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<sup>14</sup> Alcohol and Drug Partnerships

some of the failures of duty, or responsibility of several stakeholder organisations, who function on two typical forms of service provision (1) 'charity-based' service provision and (2) 'issues-based' service provision.

The charity or generosity model of service provision is predicated on a 'giving' basis to deal with social problems with the donor assuming a position of believing they know best how to help an individual in need. This model is typified by well-meaning donations of food, clothes and money to individuals deemed deserving of help. After receiving charity, the individual is left in need and remains dependent on services. This situation fosters a widely held belief that the individual is not committed to change. In the charity model there is inbuilt inequality as the needs of individuals are not able to be fully expressed (Kirkemann & Martin, 2007).

The needs-based approach is based on addressing issues highlighted by the individual in crisis. A significant difference in this approach is the inclusion of the individual or group who identify needs have some opportunity to offer potential solutions based on an assessment. This remains the dominant statutory approach in the provision of addiction treatment and mental health services. A weakness in this approach, shared with the charity-based approach, is the inability to make systemic changes to macro factors that increases risk factors and related problems faced by individuals or groups.

In effect both approaches leave recipients with a marginal voice, without the ability to engage with public organisations, or make the necessary policy or legislative changes to change power imbalances. These standard or common approaches to service provision does not actively create opportunity for individuals to acquire skills and information that they could apply to change their situation. Workers and other professionals speak and advocate for them.

Alternatively, the rights-based approach, which emerges from the international scene and particularly from post-colonial emerging nations, highlights the need to recognise the 'right to development' as a human right (United Nations, 1986).

### **Approaches to advocacy**

Advocacy is a broad term, and may refer to citizens' advocacy, group or collective advocacy, peer advocacy, and professional advocacy. Independent advocacy is considered a means to redress these power imbalances to empower vulnerable individuals. The importance of independent advocacy for vulnerable individuals was recognised by The Scottish Parliament in 2001:

*'Independent advocacy is a crucial element in achieving social justice. It is a way to ensure that everyone matters, and everyone is heard—including people*

*who are at risk of exclusion and people who have difficulties in making their views known. (Independent Advocacy—A Guide for Commissioners, Scottish Executive 2001).*

In 2004 the Scottish Executive Effective Interventions Unit published *Advocacy for Drug Users: A Guide*. The Guide posed the question ‘Could advocacy be useful for drug users?’ In response to this question the report states:

*‘Evidence shows that people who have drug misuse problems will, in many cases, have a range of other difficulties in their lives. These difficulties include problems with housing, family relationships, employment, offending behaviour and debt...The evidence from the EIU advocacy survey, consultation seminar and focus groups suggest that service users and providers consider advocacy to be an important component of effective treatment and care provision.’ (EIU, 2004).*

While the role of advocacy is enshrined in the Mental Health (Scotland) Act 2015, addiction and substance use disorders are not considered to be covered by existing mental health legislation and the Equality Act (2010).

The report from the SIAA Scottish Independent Advocacy Alliance (2013) identified the important role the independent sector could provide in supporting recovery in Scotland. The Mental Health (Care & Treatment) (Scotland) Act 2003 identifies that every person with a mental disorder (as defined under section 328 of the Act) has a right to independent advocacy. The Act places a duty on local authorities and the NHS to ensure that such services are available. In 2010, Two years after the launch of the Road to Recovery by the Scottish Government in 2008, the SIAA acknowledged that with advocacy support, individuals’ families and communities can recover and flourish from the impact of problem drug and alcohol use in Scotland (SIAA, 2010).

### **Defining and understanding rights-based advocacy**

The Danish Institute of Human Rights (2007) describes a rights-based approach to advocacy as:

*“...A rights-based approach...is able to recognise poverty as injustice and include marginalisation, discrimination...Human rights claims always have a corresponding duty-bearer. A central dynamic of RBA is thus about identifying root causes of poverty, empowering rights-holders to claim their rights and enabling duty-bearers to meet their obligations. In this way RBA calls attention*

*to a number of central features of poverty and development...” (Kirkemann & Martin, 2007: page 9)*

The Danish model of RBA indicates that viewing the individual as the cause of their social problem, in this case poverty, directing responsibility, and also focusing interventions solely at the individual is in essence an avoidance of responsibility and obligations by ‘duty bearers’.

### **Defining quality of life in the context of recovery**

As a term and as a concept, quality of life (QoL) is widespread, yet it is difficult to define and interpret as there are many factors to be considered in its definition. Aristotle in the Nicomachean Ethics discusses the good life and what could be considered its definition states:

*“...when it comes to saying in what happiness consists, opinions differ, and the account given by the generality of mankind is not at all like that of the wise. The former take it to be something obvious and familiar, like pleasure or money or eminence and there are various other views, and often the same person actually changes his opinion. When he falls ill, he says that it is health, and when hard up he says that it is money...” (Aristotle, Book 1, Ch. 4).*

Aristotle explains what remains difficult in defining what one means by QoL. Most definitions will indicate that it relates to individual perceptions, and that conceptions of quality of life will change over time. Therefore a ‘good’ QoL will be context and situationally dependent influenced by several factors. In the terms Aristotle uses, such as health and money and ‘eminence’, it is the case that there are vast inequalities in Scottish quality of life. The poor are almost certainly experiencing a very different QoL from that of the more affluent. In addition, QoL must also consider the hopes and aspirations of an individual, and in this sense, we can include access to quality rather than adequate housing, education and employment, leisure activities, relationships between family and friends, and psychological and emotional aspects of life.

The measurement of QoL is related to both objective and subjective factors of health and welfare, and other factors such as freedom from pain and discomfort, mobility, ability to think, read, talk etc. and subjectively on the individual’s toleration and acceptance of the absence of such features and the hopes of recovering these. It is this combination of subjective and objective which makes the measurement of QoL challenging.

While the definition of vulnerable adult appears clearly defined, how services interpret vulnerability in adults and what their responsibilities are to those who may be vulnerable with considerable unmet complex needs differ.

This brief overview has defined rights-based advocacy services and discussed the difference between issues-based service and rights-based services, and the challenges in providing services for individuals with complex needs.

The rights of marginalised and vulnerable individuals with complex needs who use AOD and suffer mental ill health, are inadequately addressed by needs based services. The dignity and human rights of marginalised and stigmatised individuals with complex needs is fundamental to a rights-based approach to service provision.

In addition to the characteristics that serve as a definition of vulnerability, there are other factors that contribute to make individuals vulnerable. These include:

- the knowledge gap between the providers of services (duty bearers) and their users (rights bearers) of basic human rights
- the ability of service users to judge the quality of services, even after they have received help from a service

The study seeks to gain understanding how and in what way rights-based advocacy training (RAPA) impacts on the ability of candidates (those who undertook the award) to address the complex needs of vulnerable service users. As there are no known assessment tools recognised to measure the perceptions of QoL in relation to vulnerable and marginalised individuals who are dual diagnosed, this study offers the opportunity to explore QoL in the context of recovery.

## RESEARCH AND STUDY OBJECTIVES:

1. To evaluate the impact of the rights-based Reach Advocacy practice award (RAPA) on the therapeutic commitment<sup>15</sup> of candidates who successfully completed the training.
2. To explore the Quality of Life scores of candidates and pre-candidates in recovery attending the rights-based reach advocacy service (RBAS) at the beginning of contact and at completion of RAPA training or advocacy intervention.
3. To highlight gaps in current service provision<sup>16</sup> for vulnerable clients from service user and service provider perspectives.

The methodology section explores how we:

- Evaluated the impact of the RA level 7 SCQF award on candidates (participants in the RA training) levels of therapeutic commitment using the adapted AAPPQ, administering the AAPPQ to candidates' pre and post training,
- Evaluated the suitability of using the WHO QoL questionnaire on RA clients who are in recovery,
- Administered the WHO QoL questionnaire to service users who are also potential candidates for undertaking the RAPA,
- Present an analysis of interviews with key informants including RA trainers, RAPA candidates, RA clients (pre-candidates), and service providers.

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<sup>15</sup> In this study therapeutic commitment, is understood as a commitment to a human rights-based approach (humanitarian commitment) to working with vulnerable, marginalised and stigmatised individuals with complex needs.

<sup>16</sup> Clients particularly those who are dual diagnosed, who require rights-based advocacy in the context of recovery often fail meet the criterion for help from several needs-based services, including treatment providers, social work, Housing, health, and in accessing welfare (benefits) DWP.

## SECTION 3: THE METHODOLOGY

This study utilises a mixed methodology, using an adapted Alcohol and Alcohol Problems Perception Questionnaire (AAPPQ) developed by Shaw et al., (1978) to assess the impact of the RAPA on the attitudes of candidates successfully completing the practice award. In addition, the study investigates the suitability of using the WHO QoL assessment to understand the impact of a rights-based advocacy intervention on the QoL of clients in contact with RA.

A quasi-experimental non-equivalent control group design was used to assess the influence of an SCQF level 7 RAPA on candidates in recovery who work in front line services with clients in recovery. The dual foci of the evaluation were participant's knowledge and attitudes, and these were assessed using a modified version of the Alcohol and Alcohol Problems Perception Questionnaire (AAPPQ).

The research data included into this report was conducted between August and September 2018. The new refreshed drugs strategy to address the high rates of DRD were announced in July 2018. This means that there is an interest in attempting to understand how a rights-based, rather than an issues-based service has on the QoL of vulnerable people

The ethics application was submitted to UWS ethics committee in July 2017 and approved in August 2017. Funding from GCA was secured for the research team of Iain McPhee and Barry Sheridan to conduct this work in June 2018. In addition, 21 interviews took place with a range of candidates, pre-candidates, and service providers using qualitative methods.

The beneficiaries of this approach are not only the commissioners or service providers, but also, more importantly, the users (candidates and pre-candidate service users) who benefit both from their involvement in the research and any developments it may help shape. Finally, there are further beneficiaries: those who live in communities that suffer the collateral harms of problematic AOD use, and who also suffer mental ill health related to their use of drugs and the stigma they experience as a marginalised and vulnerable group of individuals.

### **Study Limitations**

The methods used in this study have several limitations. It is apparent that studying for a level 7 SCQF award is a significant undertaking for any individual recovering from the impact of problem AOD use, or who has suffered with problems with their mental health. The numbers of

candidates who successfully completed the RAPA are small (N=10)<sup>17</sup>. RA utilise a four-stage recovery functioning model to determine the suitability of candidates to undertake the award. Candidates who have achieved stage 3 are eligible to be considered candidates for undertaking the RAPA.

The interviews that took place between the researcher and the pre-candidates (clients) of RA who may at some point become eligible to undertake the RA award, are subject to several potential biases, recognised by Becker (1969). Becker notes that researchers engaging in qualitative research find it difficult to remain detached and objective when there are power imbalances, often siding with the participants in any study. However careful acknowledging of the potential for bias was noted, and the research process took place in an open and collaborative manner between researchers, the RA trainers, service providers, and others who had no stake in the work of RA.

The results of this evaluation document the experiences of vulnerable and marginalised individuals attending a rights-based independent advocacy service (Reach Advocacy) in North Lanarkshire.

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<sup>17</sup> TBLF funded Reach Advocacy for 3 years to enable candidates to complete the RAPA. Embarking upon the RAPA is only possible when candidates are stable in recovery. However, TBLF were unable to acknowledge that recovery takes considerable time, and that not all potential candidates were stable enough to engage with the RAPA training. The Big Lottery Fund provided one third of the monies requested by RA. This reduction in funding has not reduced expectations of how successful outcomes are to be documented and achieved. There appears to be a lack of understanding that vulnerable clients require significant time to achieve stable recovery to embark upon and complete the RAPA.



#### SECTION 4: THE SAMPLE OF RESPONDENTS AND PARTICIPANTS.

In total 21 qualitative interviews were conducted between August and September 2018. Interviews took place at RA in private settings free from distractions. All Interviews were recorded on a digital recording device after consent was gained and transcribed using pseudonyms to guarantee privacy. All transcripts were analysed using adaptive coding (Neale 2015).

#### DIFFICULTY IN ACCESSING VULNERABLE CLIENTS (PRE-CANDIDATES)

Moore and Miller (1999) point out when research subjects are doubly vulnerable, facing several factors that impinge upon autonomy, there are often unique and difficult challenges encountered early in the research process. In the present study there were several difficulties in gaining access to RA clients. We interviewed eight clients (pre-candidates), and this took several weeks, due to missed appointments that had to be rescheduled. We must point out however that securing access did not halt the completion of the data collection, just that securing access to clients was at times difficult. On two occasions, the interviews took place with trained advocate workers present. While we do not believe this compromised the content of the interview, this does highlight the difficulty in recruiting vulnerable and marginalised individuals into a research study.

## SECTION 5: QUANTITATIVE RESULTS

<b>Respondents</b>	<b>Number</b>
Candidates completing the AAPPQ,	10
Candidates completing the WHO-QoL 100	10
Pre-candidates (clients) completing the WHO-QoL 100	28

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### EVALUATING THE REACH ADVOCACY PRACTICE AWARD (RAPA)

This section discussed the first of three aims in this evaluation study of Reach Advocacy.

- 1. To evaluate the impact of the rights-based Reach Advocacy Practice Award (RAPA) on the therapeutic attitudes and commitment of candidates who successfully completed the training**

The Reach Advocacy Practice Award was ratified by the SQA in 2018 (Details of training content are included in appendix 4). The SQA accredited training is vocational in design, and was accredited in 2013, and certified by the SQA in 2018: <http://www.sqa.org/sqa//66110.6550.html>

The level 7 SCQF award is designed to increase the knowledge of candidates in human rights, and the social determinants of health in the context of the recovery of vulnerable, stigmatised and marginalised individuals, many of whom will have complex needs.

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### THERAPEUTIC ATTITUDE IN THE CONTEXT OF WORKING WITH STIGMATISED GROUPS

A major theory posited by Shaw et al., in 1978 suggested that training influences attitudes relating to role security and role adequacy and that background characteristics of training participants, such as occupational role and support, are also important in determining the impact of training on attitude change. The relative paucity of research evidence of working with drug users by non-specialists prompted a mixed methods research case study of workers who were often reluctant or considered themselves untrained to work with problem AOD users (McPhee, Duffy, & Martin, 2012).

In the context of evaluating the RAPA on therapeutic attitudes to vulnerable and marginalised individuals an adapted AAPPQ questionnaire measures attitudes within the following categories, role adequacy, role legitimacy and role support.

### **1. Role adequacy**

The seminal work by Shaw et al (1978) proposed that poor responses by non-specialists in working with alcohol users were related to knowledge and attitudes which could be influenced positively using an educational intervention. The three main themes emerging from this study suggested that staff anxieties about role adequacy, role legitimacy and (role) support of them by other staff contributed overall to what Shaw et al., (1978) termed 'therapeutic attitude'. Anxieties about role adequacy concerned workers subjective feelings about their lack of knowledge and skill necessary to recognise and respond positively to alcohol problems in an effective manner. The participants in the Shaw et al study had little knowledge in this area and were therefore unable and often unwilling to respond to an area that was deemed 'specialist'.

### **2. Role legitimacy**

Workers who perceived that they lack the authority to intervene in a specialist subject are often expressed as anxiety about role legitimacy. Non-specialists are often uncertain about professional boundaries and consider that AOD clients are a mental health or specialist medical or psychiatric issue. This uncertainty is often compounded by a reluctance to intervene in domains that may be considered out with their areas of competence. This can result in reluctance to engage with AOD users.

### **3. Role support**

This aspect of the study by Shaw et al., (1978) referred to workers feeling that they were not supported by specialist services having little in common, and minimal communications with them. There was therefore little assistance in terms of advice, support and consultation about the most effective option of engaging with drinkers who were experiencing problems in their use of alcohol. It is often the case that managers and colleagues do not support workers in this aspect of their work.

These areas are considered to interact in a complex relationship and workers who exhibit these factors are described as having 'role insecurity'. This may be linked to a lack of training and

experience of engaging with what is a complex set of psychiatric and medical problems that are out with the remit of non-specialists. This role insecurity in turn fosters an emotional detachment and physical disengagement with clients with drugs and or alcohol problems termed 'low therapeutic commitment' Shaw et al (1978; Cartwright 1980). Non-specialists can be seen to be demonstrating a low therapeutic commitment, and therefore role insecurity by the following attitudes and behaviours:

- Avoiding problems in their clients by denying its existence
- Prioritising other issues over the alcohol or drug use
- Referring on to 'specialists'
- Hopelessness that nothing can be done with this client group
- Blaming drug users for the situation for lacking 'motivation' or will power to change
- Accepting and colluding with drink and or drugs use.

These attitudes and behaviours are due in a large part to the lack of adequate training to intervene in problem populations (McPhee et al, op cit). Consequently, Shaw et al (op cit) found that workers with a 'high therapeutic commitment' had four basic characteristics that strengthened their role: they were knowledgeable in working with problematic alcohol users; they were supported in this role; they had received training in working with drinkers, their knowledge of alcohol issues was good. They concluded that basic role requirements such as training, experience, confidence and support help develop 'role security' which in turn fostered and supported an improved therapeutic commitment.

### **Evaluation of RAPA graduates**

It has been recognised that specific and well-designed educational interventions can alter attitudes to enable individuals to work effectively with certain stigmatised groups, such as problem drinkers (Siegfried et al 1999, Royal College of Psychiatrists 2002). Research has documented that attitudes are strong predictors of behaviour (La Pierre 1934, Ajzen 1991, Eagley and Chaiken 1993). The attitudes, which members of certain professions hold towards the individuals for whom they care, have been found to impact on the quality of care delivered (Moodley-Kunnie, 1988), similar findings are documented for non-specialist working with AOD users (McPhee et al., 2012).

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## ADAPTING THE AAPPQ

In adapting the AAPPQ we consulted two instruments developed to assess health workers attitudes towards working with AOD users are the *Alcohol and Alcohol Problems Perception Questionnaire* (AAPPQ) (Cartwright, 1980) and the *Drug and Drug Problems Perception Questionnaire* (DDPPQ) (Watson, Maclaren, & Kerr, 2007).

The original AAPPQ and DDPPQ each feature 30 statements, such as “I feel I have a working knowledge of alcohol and alcohol related problems” and “I feel I have the right to ask patients/clients questions about their drug use when necessary.”

Respondents rate each statement on a seven-point Likert scale (1 –strongly agree; 7 – strongly disagree). The resulting analysis of results provides a measure of the likelihood that respondents will engage with vulnerable and marginalised people with AOD problems in practice settings. In adapting the AAPPQ, we included the terms vulnerable and marginalised in addition to references to AOD use and users.

The Shaw and Cartwright (1979) questionnaire is adapted for use in this study. The questionnaire allows participants to respond on a 4-item Likert scale (1- Strongly agree, 2 - Agree, 3 - Disagree & 4 - Strongly disagree). The questions include ‘I feel I have a working knowledge of rights-based advocacy’. The questionnaire consists of 22 questions. A copy of the questionnaire can be found in the Appendix 2.

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## THERAPEUTIC COMMITMENT OF RAPA CANDIDATES

The AAPPQ was adapted to measure the attitudes of candidates to work with vulnerable, stigmatised and marginalised groups. These groups included AOD users, and those suffering mental ill health as a result of AOD use.

Before the intervention, participants were asked to complete the adapted AAPPQ questionnaire which recorded a baseline measure (time period 1) of perceived skills and attitudes to advocacy and recovery in relation to role legitimacy, role adequacy, and role support identified by Shaw and Cartwright (1978) in their key study. The completed questionnaires were given a code number to enable identification of the participant at the beginning (time period 1), and at the end of training intervention (time period 2) when participants (candidates who successfully completed the RAPA) were asked to complete the post-test adapted AAPPQ questionnaire. The completed questionnaires were coded and input to SPSS. Non-completion of the RAPA excluded any participant from the data analysis.

## **The candidates undertaking the RAPA**

Included in this section are data from 10 candidates (5 males and 5 females) who successfully completed the RAPA and asked to complete the adapted AAPPQ at time period 1 pre training and time period 2, post training. The RAPA is designed to be delivered and evaluated over a 4-month period.

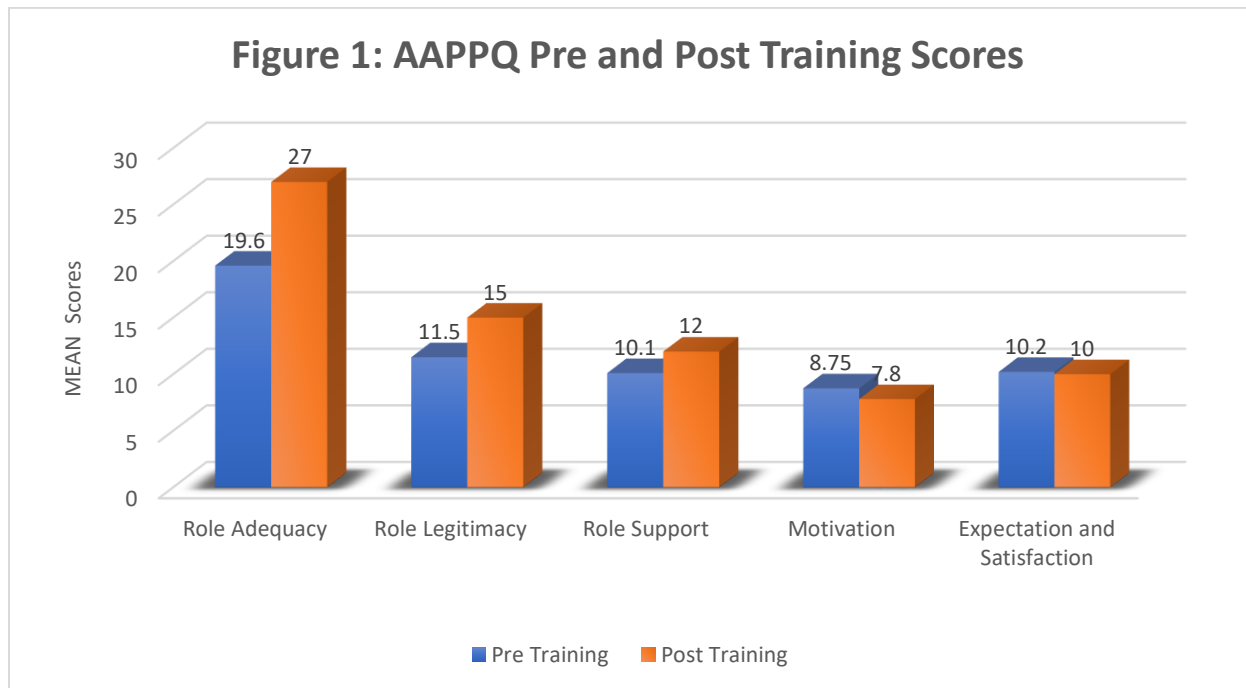
The low numbers of successful candidates competing the RAPA training are explained by several factors. Candidates in recovery may often experience difficulty at various times in their lives. There were various reasons given for non-completion, and this while not exhaustive include, the length of time taken to complete the RAPA, which has at initial delivery took up to 10 months to complete<sup>18</sup>.

Some candidates experienced several challenges during their study, and due to these difficulties opted to withdraw from study and completion.

A four-stage model of recovery utilised by RA to determine the suitability of candidates taking the RAPA. Individuals at the early stages of their recovery from AOD problems and mental ill health are often unable at this early stage to commit to such a lengthy time period of study. Therefore, the low numbers are also explained by the fact that only candidates in stage 3 (stable recovery and abstinent for several years) were able to embark on the RAPA.

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<sup>18</sup> The open-ended attitude to completion was recognised by RA trainers as a difficulty. They recognised that an open ended attitude to assessment completion impacted upon the numbers of candidates eligible to compete the AAPPQ at time period 2.



**Role adequacy**

In Figure 1 ‘AAPPQ pre and post training scores’ for the domain role adequacy indicates a significant shift in attitudes with a pre-intervention (time period 1) score of 19.6 to a post training (time period 2) score of 27 for candidates in role adequacy. This suggests that increased knowledge of a rights-based approach to advocacy increased perceptions and confidence in working with vulnerable client groups.

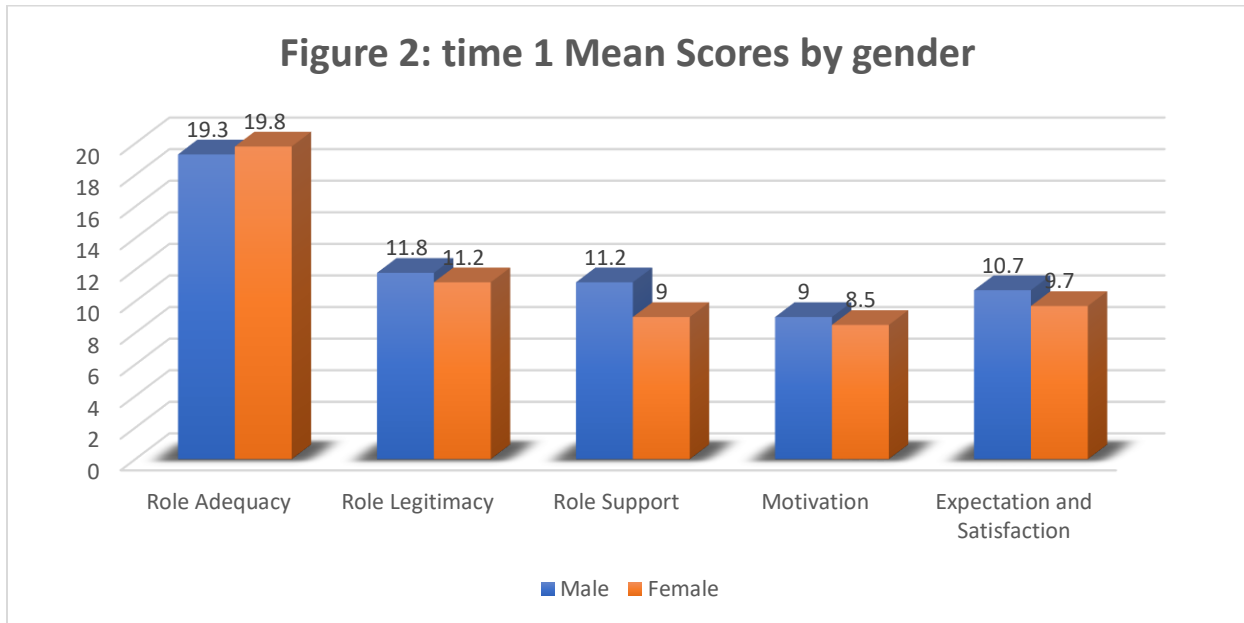
**Role legitimacy**

In like manner the shift pre-intervention of 11.5 (time period 1) to 15 post award training (time period 2) indicates that increased knowledge post award fosters a positive attitude in recognising that vulnerable clients are a legitimate focus of the role and responsibility of Candidates in engaging with vulnerable and marginalised groups.

**Role support**

An increase from 10.1 (time period 1) to 12 post training (time period 2) is a rather modest increase in perceived role support to engage as advocate workers. This suggests that while therapeutic commitment has altered positively noted by the time period 2 score increases in role legitimacy and adequacy. Candidates who engage with and advocate for vulnerable and

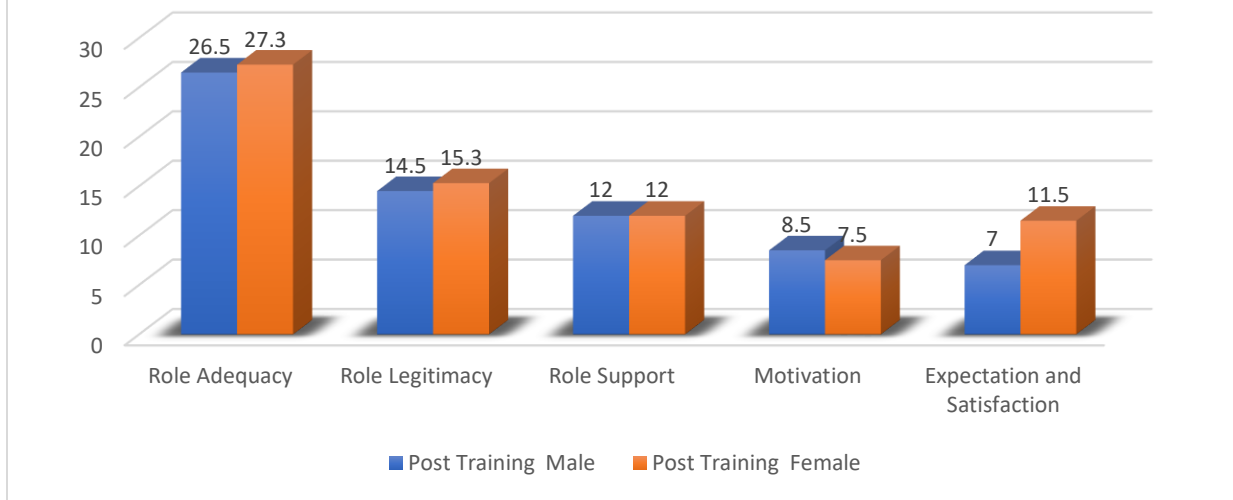
marginalised individuals require to be supported in the environment in which RAPA candidates work. The presence of these factors enhances motivation to work with problem drinkers, increased expectations of satisfaction, and professional self-esteem when engaging with clients (McPhee et al., op cit).



In Figure 2 'time 1 Mean Scores by gender,' there were few recorded differences related to gender. Male respondents (N=5) scored slightly lower in the domain role adequacy, and slightly higher in the domain scoring role legitimacy. The greatest differences is recorded in lower perceived role support by female (n=5) respondents scoring 9 (time period 1), while male candidates scored 9 (time period 1).



**Figure 3: Candidate time 2 Score by gender**



In Figure 3 'Candidate time 2 Gender Mean Scores' there were overall shifts in terms of perceived role adequacy in the time period 2 scores, indicating the correlation between increased knowledge and increased positive attitudes expressed by candidates in expressing how suitable they considered themselves to be to engage with stigmatised and vulnerable groups.

### **Discussion**

Figure 2 indicates a score of 19.3 for males, and 19.8 by females at time period 1. Table 3 indicates that in time period 2, males score 26.5, while females score 27.3.

In role support there are modest increases for males 11.8 and females 11.2 at time period 1 in Figure 2, while table 3 indicates a modest increase to 12 for males and females at time period 2. Figure 2 indicates a score of 9 for males and 8.5 for females at time period 1 while Figure 3 indicates a reduced scoring to 8.5 for males and 7.5 for females at time period 2.

The greatest difference is perceived expectations and satisfaction in working with stigmatised and vulnerable groups by female candidates. Figure 2 indicates a score of 10.7 for males and 9.7 for females. Figure 3 indicates a score of 7 for males and 11.5 for females at time period 2.

## **Motivation, expectation and satisfaction**

In relation to scores for motivation, the (time period 1) score of 8.75 declining to 7.8 (time period 2) is difficult to explain. This may be due to the low numbers of candidates who completed the AAPPQ at time period 2. There is also a modest decrease from 10.2 at time period 1 to 10.0 at time period 2 in relation to expectation and satisfaction. This may be an artefact of expectations of working within agencies that routinely stigmatise AOD users, despite the RAPA candidates having increased knowledge of rights-based advocacy, in the context of recovery. To fully explore this more research with a larger cohort is required.

## **Discussion and conclusion**

The RAPA training award is based on providing successful candidates a working understanding of equality and human rights legislation in relation to the rights to health and social care, and the social determinants of health, in the context of recovery.

Shaw et al (op cit) found that workers with a 'high therapeutic commitment' had four basic characteristics that strengthened their role: they were knowledgeable in working with problematic alcohol users; they were supported in this role; they had received training in working with drinkers, their knowledge of alcohol issues was good. They concluded that basic role requirements such as training, experience, confidence and support help develop 'role security' which in turn fostered and supported an improved therapeutic commitment.

Successful completion of RAPA training significantly increases mean scores of the adapted AAPPQ. While these increases are modest, they do indicate a positive change in therapeutic commitment at time period 2.

While the numbers of successful candidates completing the SCQF level 7 award are low, (N=10) there are reasons for this. The RAPA award is intended to be undertaken by candidates who have worked as a volunteer with an agency, cleared to work with vulnerable and marginalised groups, and report stable recovery from AOD use and mental ill health for a significant period of time.

- 2 To identify changes in the Quality of Life of candidates and pre-candidates attending the rights-based reach advocacy service (RBA) at the beginning of contact and at completion of RAPA training, in the context of recovery.**

### **Procedure and study instrument**

In this study, 38 (10 candidates, and 28 pre-candidates) WHO-QoL-100 questionnaires were completed by participants. All participants were informed that their responses would remain confidential. A trained Advocacy Worker was present to explain how to complete the WHOQoL-100 at time periods 1 and 2.

While the researchers were hoping to be able to use the WHO-QoL-BREF, (first developed and trialled in 1976) at the time of this evaluation, permission to use this much shorter 26 question questionnaire had not been granted.

The decision to use the WHOQoL-100 to measure QoL in the context of recovery was taken by RA. In this sense, all measures of QoL are to be considered in this context. Therefore, there was a working hypothesis that stage of recovery would be relevant when analysing the WHO QoL-100 questionnaire results, and that the longer an individual was in recovery, the higher their QoL scores would be.

### **Rationale for use of the WHOQoL-100 questionnaire**

The World Health Organisation-QoL instruments place primary importance on the perception of the individual. Most assessments in health care and support services are obtained by examinations by health workers and laboratory tests. The World Health Organisation-QoL instruments by focusing on individuals' perceptions of their well-being, provide a holistic perspective of QoL beyond simple assessments of physical and mental health, or absence or presence of illness and disease. As such, the QoL per se, has been described as:

*"...the missing measurement in health" (Fallowfield, 1990).*

The WHO produced the WHO (1995) Field Trial to determine which 100 questions were best suited to measure QoL when developing the QoL-100. At this trial they describe the 3 main drivers for the development of the WHOQoL-100 to define quality of life:

*“[an] individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.”*

<http://www.who.int/healthinfo/survey/whoqolqualityoflife/en/index1.html>

There is considerable consensus in relation to what QoL is measuring, and agreement that the WHO QoL-100 goes beyond simple medicalised measurements of mortality and morbidity, the impact of disease on activities and disability as measures of health.

## The WHOQOL-100

The structure of the WHOQOL-100 reflects the issues that a group of scientific experts as well as lay people in each of the field centres that trialled the WHOQoL-100 consider important to quality of life. The six broad domains of quality of life, and the twenty-four facets covered are shown in table 1 below. Four items are included for each facet, as well as four general items covering subjective overall QoL and health, producing a total of 100 items in the assessment. All items are rated on a five-point Likert scale (1-5).

Table 1: The 6 WHO-QoL-100 measurements (domains) of quality of life					
Domain 1: Physical	Domain 2: Psychological	Domain 3: Level of Independence	Domain 4: Social Relationships	Domain 5: Environment	Domain 6: Spirituality/Religion Personal Beliefs
Pain & Discomfort	Positive Feelings	Mobility	Personal relationships	Physical safety and security	Spirituality/Religion Personal Beliefs
Energy and Fatigue	Thinking, learning, memory and concentration	Activities of daily living	Social support	Home environment	
Sleep and Rest	Self-esteem	Dependence on medication or treatments	Sexual activity	Financial resources	
	Bodily Image and appearance	Working capacity		Health and social care; availability and quality	
	Negative feelings			Opportunities for acquiring new information and skills	
				Participation in and opportunities for recreation -leisure	
				Physical environment: (Pollution/noise, traffic)	
				Transport	

Table 1 documents the domains within the WHOQoL-100. In scoring the QoL -100 the domains of financial resources are incorporated into the domain of environment, indicative of the 6 measurements incorporating 7 domains.

### **Administering the WHOQoL-100**

Permission to use the WHOQoL-100 was granted on (28<sup>th</sup> April 2017, see appendix of copy of agreement) and a RA trainer was qualified to administer it.

The questions in the QoL-100 relate to the definition of Quality of Life as individual perceptions of position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHO QoL Report 1995:2).

Prior to administering of the WHO-QoL the respondent is asked to consider their life in the previous 2 weeks.

There are few studies in this area regarding understanding the impact of being labelled an addict and living with a mental health condition.

The QoL-100 provided an evaluation of QoL of service users (defined as pre-candidates) at the beginning and at the end of contact with a rights-based advocacy service (n=28).

In addition, we also measured the QoL of a selection of successful candidates (individuals in recovery who completed the RAPA).

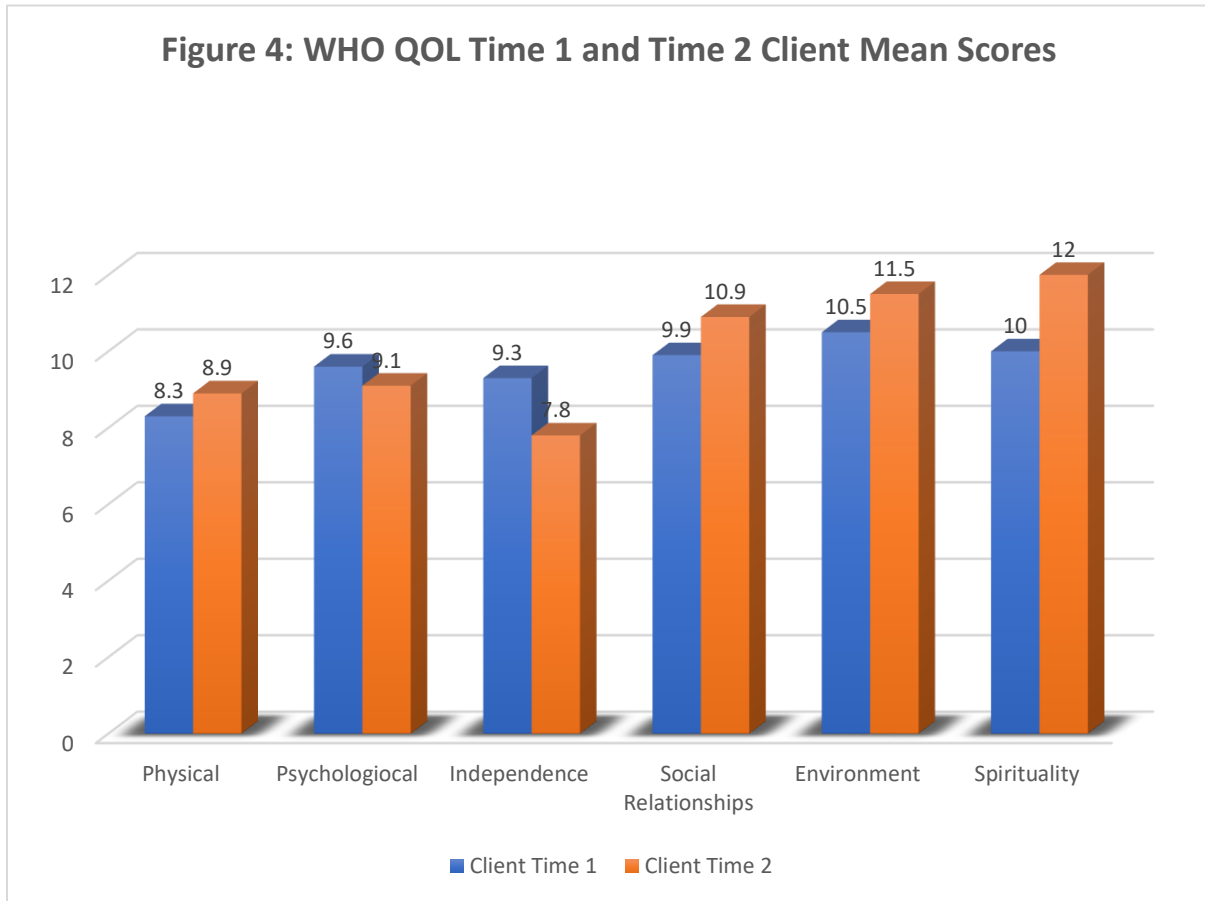
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### **QUALITY OF LIFE IN THE CONTEXT OF RECOVERY**

The term clients (also known as pre-candidates) refer to vulnerable and marginalised individuals who contacted or were referred to RA and required advocacy to engage with health and treatment services, Housing, the DWP and Social Work. At initial contact, and assessment of unmet needs, clients were asked to complete the WHO QoL-100. While some clients were able to function without support from RA when asked to complete the WHOQoL-100 at time period 1, several were still attending RA for support when asked to complete the WHOQoL-100 at time period 2. This served to make analysis of QoL scores challenging.

Pre-candidates (n=28) QoL scores were recorded at 2 time points, at initial contact (time period 1), and after receiving help and support from RA (time period 2). There was a ten-month gap

between time period 1 and 2, and some pre-candidates were still in contact receiving support from the RA service. Figure 2 below documents the mean QoL scores for pre-candidates.



### **Physical domain**

Figure 4 indicates that scores on the physical domain is a positive change from 8.3 at time point 1, to 8.9 at time point 2. This domain measures perceptions of physical health, reported pain and discomfort, and reports of sleep and rest over the previous 2 weeks.

### **Psychological domain**

In the psychological domain, there is a slight decrease from time point 1 of 9.6 to 9.1 at time point 2. This domain measures perceptions of memory and concentration, levels of self-esteem, and perceptions of body image.

### **Independence domain**

In the domain of independence, the score is 9.3 at time period 1, and reduces to 7.8 at time period 2. Questions relate to perceptions of physical mobility to move around the home, ability

to access transport to attend work or appointments, and perceptions of quality of life related to activities related to their experience of daily living. This domain also explores the client's perceptions of ability to self-care, and perceptions of caring about personal property. The focus is on ability to perform on a day to day basis. The degree to which respondents are dependent on others may also significantly influence QoL scores.

The independence domain questions explore the dependence on medication or medical support for daily living. In some cases, side effects of medications may have negatively impacted on the low score at time period 2. The questions related to working capacity explores the respondent's perception of capacity to work, and includes paid and unpaid work, voluntary work, and involvement in education. This domain also measures perception of ability to care for children and household duties with a focus on the ability to do so.

### **Social relationships**

In the domain of social relationships, perception of social relationships, and of sources of social support are reported. Also, within this domain, perceptions of happiness, perceptions of levels of sexual activity and satisfaction are reported in this domain. At time period 1 the score is 9.9 rising to 10.9 at time period 2.

### **Environment**

In the domain of environment, there is a positive change from 10.5 (time period 1) to 11.5 (time period 2). Questions in the domain of environment address 4 items related to measures of meaning of life, exploring how clients had engaged with their home environment, perceptions of feeling more secure, acquiring new skills. Increased uptake in accessing health and dental care, often making appointments themselves. Also, higher time 2 scores are the result of reported reductions in threatening letters from housing arising from accrued debt related to rent and council tax and reduced fear of losing their rights to accommodation.

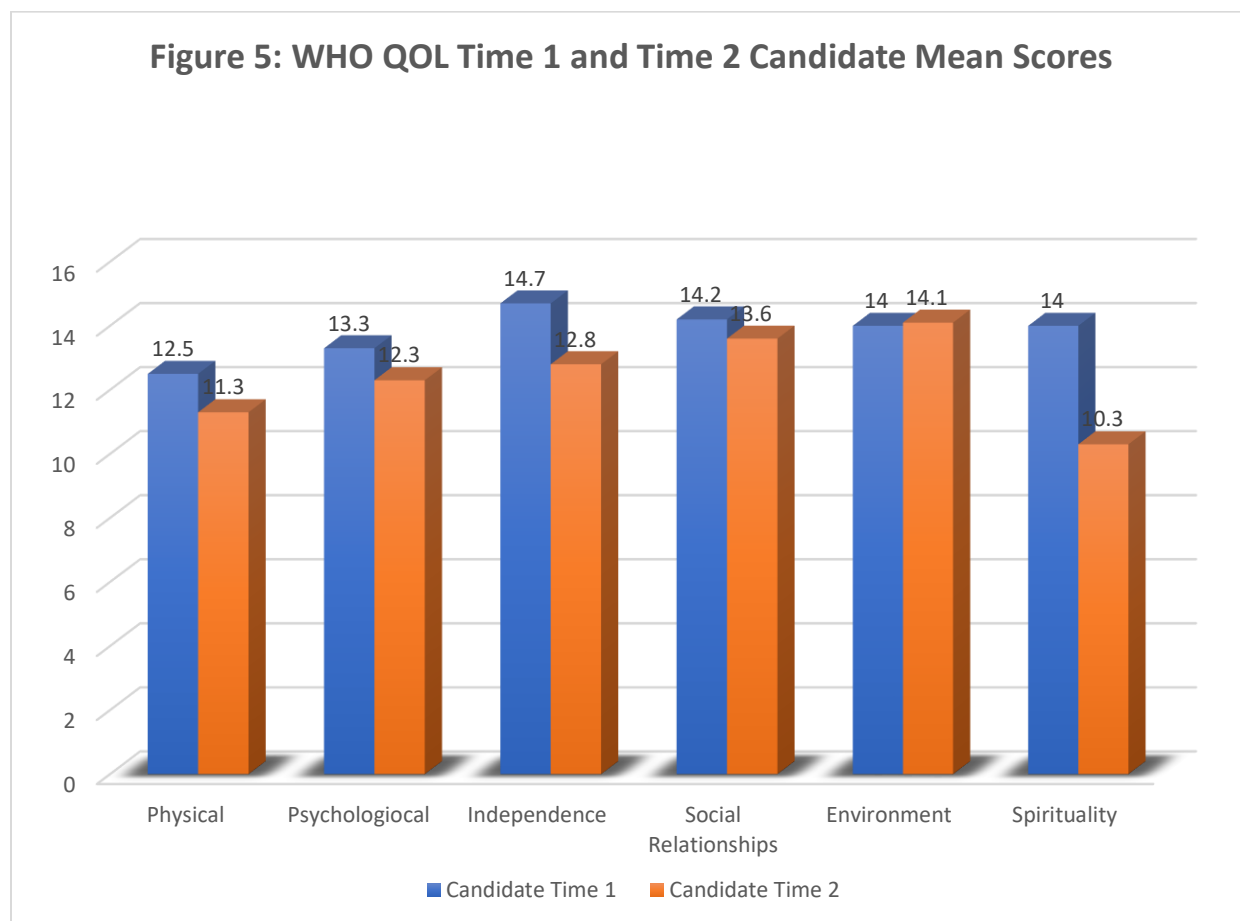
### **Spirituality**

The higher scores related to spirituality 10 at time period 1 to 12 at time period 2, can be explained by either re-engagement with a religion, previously neglected, or related to personal beliefs. In reference to Maslow's hierarchy of needs, their basic needs were accommodated or addressed, after contact with the RA service. In many ways, this domain may also document increased individual agency of clients (pre-candidates) attending the RA service.

### Candidate Quality of Life scores pre and post RAPA Award

There was an expectation by administering the questionnaire to candidates who successfully completed the RAPA, that there would be positive changes in some of the domains at time period 2.

As all candidates (n=10) who completed the RAPA were considered to be in stable recovery, these lower scores at time period 2 are interesting. This may also be a function of the low numbers of candidates included in this part of the evaluation.



In order to interpret the data in Figure 5, and the reduction in scores between time 1 and time 2 in five of six domains (the exception being environment), we note that many candidates who successfully completed the RAPA reported stressful events occurring in their lives when time 2 QoL was measured.



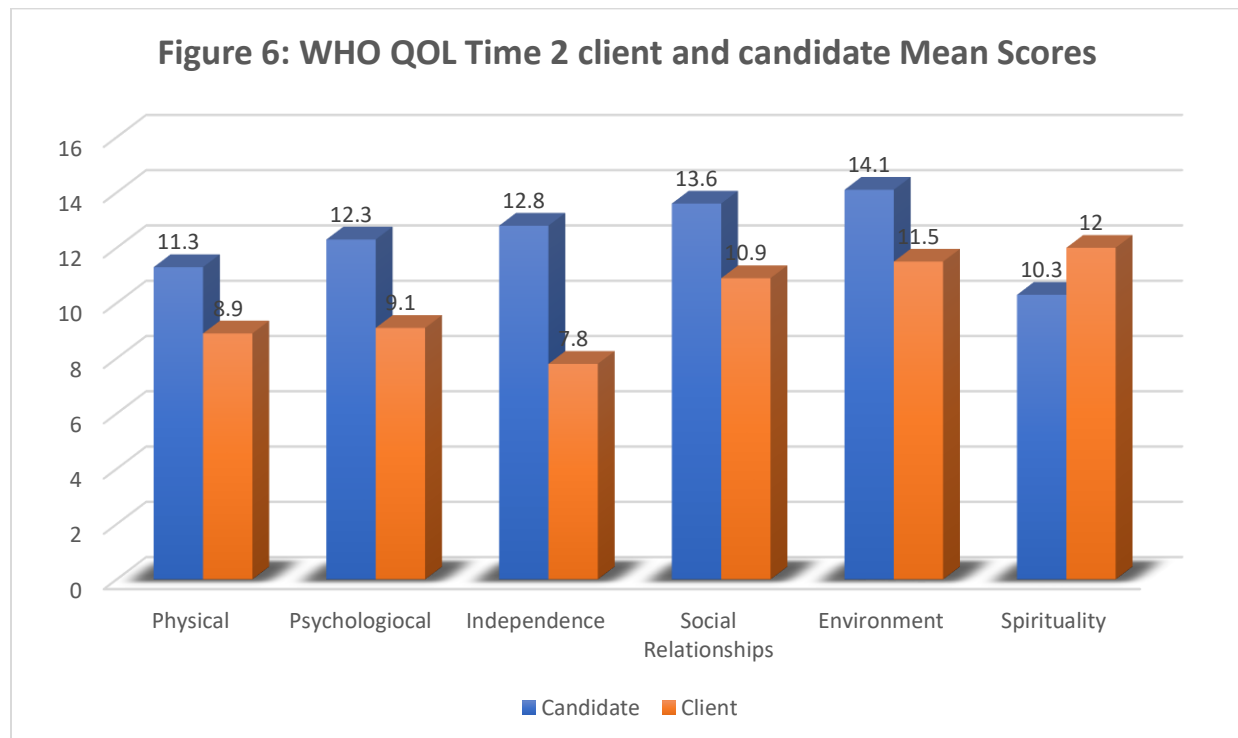
Despite the adverse personal circumstances some of the candidates were experiencing, documented as low QoL scores, the candidates had resilience to complete the RAPA.

The higher score at time period 2 in the domain of environment could be related to the fact that they perceived they had greater skills after completion of the RAPA. Questions in the domain of environment address 4 items related to measures of quality of life, exploring candidates' perceptions of feeling more secure, and having acquired new skills.

### Comparing Candidate and client's perceptions of QoL: time period 2

In this part of the evaluation we compare the QoL scores of candidates who successfully completed the RAPA (n=10) with clients (pre-candidates) who were attending the RA service (n=28).

We expected to find high QoL scores higher for candidates who were more stable in their recovery from problem AOD use, and in stable recovery from reported mental ill health. The time period 2 scores are documented in Figure 4 below comparing candidates and clients (pre-candidates).



We took the decision to compare the candidate and client pre-candidate QoL-100 scores at time period 2, after completion of the RAPA award for candidates, and after being in receipt of the RA service for clients in order to discuss the QoL scores in the context of recovery.

As recovery is a long-term commitment, and in some cases even life long, the working hypothesis, was that candidates in longer term recovery would score higher in the QoL-100.

The 'WHO QoL Time 2 Mean Scores' in table 7 indicates the stark differences in perceived QoL between pre-candidates (clients in attendance at RA and requiring support during their recovery) and candidates who successfully completed the RAPA training award.

It is noted that time is an important variable in achieving and maintaining recovery as recognised by Best et al., (2010). Therefore, we expected that scores for clients would be lower than candidates completing the RAPA training. Results highlighted in figure 6 indicate that this was indeed the case. We acknowledge however that the results may be an artefact of the differences in numbers of candidates (n=10) and clients (n=28).

### **Physical domain**

In the physical domain candidates score 11.3 while clients score 8.9.

### **Psychological domain**

Candidates score 12.3 documenting features of psychological well-being, while clients score 9.1.

### **Independence domain**

In rating independence, candidates score 12.8, while clients score 7.8.

### **Relationships domain**

In the domain of social relationships candidates score 13.6, while clients score 10.9,

### **Environmental domain**

In rating environment (which also includes financial security) candidates score 14.1 while clients score 11.5.

### **Spirituality domain**

It is only in the domain of spirituality, that clients score 12, while candidates score 10.3. There may be several reasons for this. In the early stages of recovery, many of the pre-candidates (clients of RA) were in contact with self-help or 12 step-based recovery groups and related self-

help formal and informal services. These services promote the philosophy of seeking help or understanding that help can be a spiritual journey, however defined.

### **WHO-Quality of Life results discussion**

It is worth noting that some clients completing the QoL-100 were still engaged with the RA service, requiring advocacy support at time period 2. RA work with clients on average between 8-10 months. Some clients, previously reporting stability, may present on occasion in distress and in crisis. Therefore, as some clients report being in crisis at time 2 scoring, this explains the slight reductions in psychological and independence domains.

While we expected all change to be positive (increased) for time period 2, the reductions in scores at time period 2 are perhaps an artefact of being offered help and support during times of crisis, and where RA have linked clients to other sources of support such as GP's, Veterans First support, Jobcentre Scotland work coaches, housing officers, to ensure that clients perceive themselves to be active agents in their own recovery journey.

RA offer the scaffolding of support, however, take steps to encourage and empower clients to engage with these agencies, making appointments, challenging decisions, and being proactive in engaging with DWP, for example in work capability assessments.

At this time, during challenging times, reported levels of independence and psychological domains are explained by this transition from dependence on a service to become self-assured, empowered, and independent, as part of their recovery.

### **Recovery-oriented quality of life**

The rationale for the use of the WHO-QoL-100, removes discussing the quality of life from the discourses of disease, dependence and addiction, which are heavily stigmatised. Measures of recovery capital document strengths and weakness in achieving recovery based on the individual perceptions, however such measures ignore the experiences of vulnerable and marginalised clients engaging with DWP, social work, and other state surveillance agencies.

The notion of time is a crucial factor in how recovery is understood and achieved. Maslow's Hierarchy of needs theory (1948) documents factors necessary for achievement of meaningful participation in life. His construct of needs are conceptualised as a pyramid. Maslow notes that basic needs must be met, before one can consider engaging in activity beyond the basic necessities of life further up the pyramid. From the bottom of the *hierarchy* upwards, *needs*

include physiological, safety, love and belonging, esteem and self-actualization. Maslow posits that *needs* lower down in the *hierarchy* must be satisfied before individuals can attend to *needs* higher up.

When measuring the QoL of individuals in recovery, it should be noted that for many individuals in early stages of recovery, often in crisis, the last thing many clients (pre-candidates), are considering is their QoL in the context of higher needs. If they have lost access to treatment services, welfare (benefits), are in arrears with housing and council tax, they may be unable to focus on anything other than basic needs.

As the candidates scored higher than clients in QoL scores, we can suggest that while more research is required, the WHOQoL-100 is useful in documenting QoL in the context of recovery.

## SECTION 6: QUALITATIVE RESULTS

In this section we explore aims 3

- Aim 3: To highlight gaps in current service provision<sup>19</sup> for DD clients from service user and service provider perspectives.

<b>Interview No.</b>	<b>Pseudonym</b>	<b>Identity</b>
1	Ms K1	RAPA Candidate
2	Ms S	RA Volunteer, RAPA Candidate
3	Mr D	RA Trainer
4	Mr B	RA Client
5	Mr M	RA Client
6	Mr T	RA Client
7	Mr R	RA Client
8	Ms K2	RA Volunteer
9	Ms M	RA Volunteer
10	Mr S	RA Client
11	Ms B	RA Client
12	Ms J & Ms M	Service providers
13	Ms K3	RA Client
14	Ms P	RA Client
15	Mr DC	RA Volunteer, Service provider
16	Mr J	RA Trainer
17	Ms M	RA Volunteer
18	Mr D	RA Volunteer
19	Mr N	Service provider
20	Mr G	MSP

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<sup>19</sup> Clients or pre-candidates accessing rights-based advocacy often have failed to meet the criterion for help from several agencies, including housing, health, DWP.

## RA CLIENT CASE STUDIES

Initially all 21 interviews were transcribed and thematically coded for analysis (Neale, 2015). The transcriptions were read to select the main themes occurring from the content of the interviews and the principal findings extracted. Coding allowed the analysis of the data to be put into categories and from these categories themes in the data were identified.

We present 10 case studies from transcribed interviews with RA clients (pre-candidates) to highlight how and in what way their experiences led them to seek help from Reach Advocacy (RA) rights-based advocacy service.

The interview schedule (see appendix) gathered demographic data of each participant interviewed (age, sex, occupations status, education, and postcode). In addition, the semi structured interview schedule allowed reflexivity in how and in what way questions were asked. The questions investigated participant views on understanding the needs of vulnerable people, on addiction, on dual diagnosis, on the lived experiences of interacting with various services, including addiction and or mental health services, and the Department of Work and Pensions (DWP). In addition, questions were used to explore the theoretical components of how and in what way the RAPA award training content was conceived, and how it has been applied in practice.

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### INTERVIEW 4: MR B

Mr B struggles with sobriety from alcohol, chaotic use of cocaine and mental ill health. He is poorly educated, possibly due to dyslexia as he reports being unable to write English, although he can read well. Mr B suffered a serious life changing injury while working as a construction worker and is registered disabled after losing a significant part of the muscle mass in his left arm. He has accrued significant debts due to unpaid rent and council taxes linked to chaotic alcohol use, mental ill health and work-related injuries.

He is also in regular attendance at Phoenix to monitor his use of alcohol. He is not abstinent from alcohol and describes himself as a controlled drinker. He does not use any illegal drugs. He has not reported a relapse for several months.

RA advocated for him, and created a plan to address his debts, helped him with his medical assessment at DWP, and advised him on the benefits he was entitled to.

*"I suffer from mental issues – depression, psychosis, which I'm getting help for...I'm only drinking because I have no self-worth. (When) I was 18, 19, I thought I was top of the world, now look at me – I'm going to foodbanks to get my messages and that" (Mr B, RA client)*

### **Could you explain why people develop drug problems?**

*"Depressed. Because of the social, economic situation. They're so depressed with their lot. You know, the place is miserable, everybody's junkies. People think, 'fuck it', they just want 10 minutes of peace. And they're banging a load, and if they don't bang enough then they take another bit and that doesn't work, they need to take the lot in the one go" (Mr B, RA client).*

### **How have RA helped you?**

*"Can I just start at random? The work that RA do here is phenomenal. I was in a very fragile and vulnerable place last October (2017), I was at my wits end and could have gone either way. I could have ended up depressed or doing myself harm... and I met a friend who told me about the advocacy services he'd been through and he was in recovery from alcohol abuse as well. I came to see RA, they made me feel totally at ease and, I can't explain to you, how much they have helped me – I was in so much debt, I was suicidal, I had no idea where to turn. I was going to go to the Citizen's Advice, but they would have just told me to do the phone calls and letters by myself, but I was in no fit state to do these things myself" (Mr B, RA client)*

*"I didn't know there was help, but in the time, in the depths of it, I was just burying my head and not dealing with my debt. You've got to deal with your debt, cos it will catch up with you. I know, that in Scotland, nobody can come into your house and take stuff out your house, right? It's not like England but see when you're not well and you're getting threatening letters through... they do mentally affect you. I come here to RA and (they) phone them up and say, 'just leave him alone just now' – cos I am, I am going to deal with my debt. I feel like if I were to phone them myself, they would try and walk over me, you know what I mean? Whereas (RA) are a go-between, like a buffer – a buffer between me and the scary people. That's the only way I can put it, these people are scary people, the Council Tax office- they're scary people" (Mr B, RA client).*

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## INTERVIEW 5: MR. M

Mr M is 49 and has had been a problem AOD user for much of his adult life. His mental health problems began when he lived in Aberdeen, and due to his alcohol and drug problems he was subject to constant threats of violence for non-payment of debts. His younger brother, who lived in Aberdeen, was killed after a violent incident, which resulted in the mental deterioration of Mr M. Mr M returned to Glasgow, and on advice from his father, went to his GP to seek counselling help. He was prescribed medication which after a short time he did not wish to continue with. His father, concerned at his anxiety, persuaded Mr M to seek help from psychiatric services. At initial assessment he was prescribed Quetiapine, marketed as Seroquel, an antipsychotic used for the treatment of schizophrenia, bipolar disorder, and major depressive disorder. He asked on several occasions to have his dosage reduced and put on other less debilitating medication. Mr M is quiet, softly spoken, and unassertive. His difficulty in communicating with medical staff resulted in frustration, and he felt that he was diagnosed incorrectly with a non-specific psychiatric disorder and prescribed medication against his will.

He reports using heroin and other depressant type drugs to cope with his anxiety. Mr M has had several relapses and is now on a methadone maintenance prescription. He mentioned at interview that if he takes his medications as prescribed, he cannot fully function, and had he taken his anti-psychotic, he would not have made the interview, as it in his words 'wipes him out the next day' if he take his prescribed drugs as indicated. He has been in contact with RA, to have an advocate present when dealing with the DWP, and treatment services.

*"People with dual diagnosis? I fall into that category myself, I have a diagnosed mental disability in a sense for quite a number of years now, and also a dependency on alcohol and drugs, but it's good to know that there is help available. It would be more difficult I feel if you were left on your own, it would only get more difficult without help" (Mr M, 49, RA Client).*

*"I came back from Aberdeen about 19 years ago, I was staying in Aberdeen and unfortunately, I lost my younger brother who was addicted to drugs, and unfortunately it took his life, it broke me at the time, my whole world came crashing down about me, and I was just stuck there totally helpless...After coming back from Aberdeen my doctor put me on anti-depressants and after a short period of time, I just felt that this was not working for me. I can't really describe why, I just felt at the time it was not working for me. My dad said we should go and see someone at the hospital. And I went to see a psychiatrist. and it led to them trying to figure out if I was hearing voices, but to be honest with you, and because I was not fully understanding myself what was being asked at the time, and at the time I was having my own interpretation, that I*



*ended up just practically agreeing with them, just to get out of there. So, I ended up getting put on tablets, and then over time, I tried to come off them myself. And then I would go back on them. Basically, I was just hurting myself. Because the drugs that they were giving me, were for like someone who is like mental, to deal with the workings inside the head like, you know what I mean? (Mr M, 49, RA Client).*

*“...they (Psychiatric Nurses) were asking me if I was hearing voices, but I was not hearing voices, I was trying to say exactly what my problems were. They were talking a different language to me, about hearing voices, but I was not given a full diagnosis by a doctor, and I am given drugs for paranoid schizophrenia, and I used to be on 400 milligrams of a terrible psychiatric drug. I am trying to get off them, but they tell me it’s not safe to come off them” (Mr M, 49, RA Client).*

*“With my medication, trying to say that my meds were not being monitored properly, but with the methadone, and the medication, it just knocks me out. If I take methadone and my meds, and I have an appointment, then I have to not take them, or I am not making that appointment. But I have had problems for 19 years trying to get off this medication. They made their assumptions, about my diagnosis about what they think my problems are, but I disagree, because my situation is not monitored over time. For 19 years, the problems I had were real, with my brother passing, and the troubles I had were real, but I did not need medication. I needed help” (Mr M, 49, RA Client).*

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#### INTERVIEW 6: MR. T

Mr T is 61 and has been registered disabled since he had a work-related accident at 17, which resulted in losing part of his left arm, and most of the fingers on his right hand.

He has never worked and was a full-time unpaid carer for his sister whom he looked after until her death. Mr T was in receipt of DLA, which was taken from him after an initial medical assessment by the DWP in Glasgow. After being told he was fit for work, and must attend the Jobcentre, his mental health suffered, and he developed alcohol problems caused by severe depression. He was sanctioned by the DWP several times and was in debt to the local authority for both rent and council tax. His contact with RA resulted in his benefits being reinstated. He

reports that his mental health and alcohol problems were the result of how he was treated by the DWP.

*“A couple, of years ago, I was completely sound apart from the (physical) disability, and I was caring for my sister who is 76 and I got letters from DWP, and I was to be assessed, and told them the truth exactly, and they cut off my benefits. Then I went to the Jobcentre, and they told me I should not be there. I went to the doctor as I had taken a mental breakdown actually because they were taking my housing benefits away, and if they had taken this away, I would have been out of the house, and my sister would have been on her own. My sister was on constant 24 hours care, she was on oxygen 24 hours a day. I was caring for her, I did not claim carers allowance or anything like that. I just did it because she was my sister. She died last year”.*

*“It’s been really hard mentally the last couple of years. Every time I see a letter from DWP, I think what it is this time? What is this for? Since then I have been in three times now. I have depression and anxiety, if I am in a room with people, I can’t cope, and I used to be the life and soul of any party, but not now”.*

*“I thought, where do I go for help, I went to Citizens Advice (CA), but they are overrun. But they wanted me to go to a tribunal, but there is no way I could go to that. Shaving, getting ready was impossible, getting ready and trying to cope with my sister, it was awful. But then I found RA 2 years ago. And it’s ok now... I went into the DWP, and it broke me the first time. So, having someone to go in there with you, that is a great help, with my mental health”.*

*“Its things like filling in forms, to get them in order, the stupid wee things, then you are phoning these people up, and they say no this is the wrong department, and it is taking a while to get through, and you’re panicking, the pressure on you is ridiculous”.*

*“They (RA) have written letters, phoned, went with me to DWP, and for the PIP interview. I knew nothing about money and benefits. They said to me that there were things that I was entitled to. It was fantastic to have someone to advocate for you. You don’t know what is happening, I was not mentally well in dealing with them. You don’t know what is happening to you, they can be typing anything on their computers. They add things which were not written and discussed at the assessment. That is what happened to me. I was on the phone the first time and I asked to go through a tribunal. They told me I*

*needed to go through a mandatory reconsideration. The report they mailed to me, you would have thought it was for someone else, it was absolutely scandalous. It did not in any way correspond to my situation” (Mr T, 61, RA Client)*

*“I would love to see the statistics in five years and see the amounts of people that have been cut off from benefits, their cars taken from them, people, who are physically disabled, and see what happens to their mental health. I'll bet that we will see massive problems with alcohol and drugs. How many people have to die because of this? Families break up, marriages break up. Kids go downhill because kids don't have access to transport, a car. Cutbacks are everywhere” (Mr T, 61, RA Client)*

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#### INTERVIEW 7: MR. R

Mr R is 51, and currently unemployed. His former partner, a chaotic AOD user left him with a five-month-old baby to support on his own. Being a male single parent was difficult for him, and he reports developing a drinking problem. Mr was reported to Social Work for arriving intoxicated to pick up his daughter at her school. Eventually SW removed the child from his care, and he struggles to remain abstinent for long enough to have his daughter live with him again. His daughter, now 12, lives with his sister. Mr R has access to his child every weekend. He attends a recovery group with Phoenix. Mr R reported the difficulty in finding regular employment. Moving from one job to another, he found it difficult to keep up with the paperwork required to inform the DWP and his Housing Association of his constantly changing circumstances, this led to an over payment by DWP, and over a year managed to accrue £5000 debt. After contacting RA, he now has payment plan, and RA advocate for him when dealing with DWP, Housing, and in accessing treatment.

*“I have been a single parent for 12 years to my young daughter. It was a struggle at the start, but once you get into a routine, it's ok. That is quite an achievement, I think”.*

*“A couple of things since then though have gone pear shaped, my alcoholism, my depression, my mental health. I picked my daughter up from my school, and I was late, after being in the pub, and was reported to SW. They said I needed help for my alcoholism. I have relapsed a few times. Now my daughter stays with my twin sister to prevent her going into foster care. I do get access at weekend, and I am looking forward to that” (Mr. R, 51, RA client).*

*“At the (Social Work) panel meeting to get access to my daughter I did not know who to turn to. The Social workers were never the same, they were often off sick, or (had) left. But RA helped me with gaining access, to go to meetings, they helped me with expenses to get to appointment for SW hearings”.*

*“You just tell the guys at RA the truth, and they help you. I stopped getting child tax credits about a year ago, and I was on working tax credits, and when I was working, I informed the DWP when I stopped working, but they kept paying me, and being an alcoholic, I used the money. Being a single parent, this caused me hardship. I don’t mind paying it back, though. But I was using the money not just for alcohol, but I used it to buy my daughter clothes for school... I attend Phoenix and do the SMART recovery addiction programme. I do my universal credit and get help from RA for that” (Mr. R, 51, RA client).*

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#### INTERVIEW 8: MS K2

Ms K is 53, A RA volunteer, and Candidate who has not completed the RAPA. Ms K2’s interview is included as she works as an Independent Prison Monitor. The role is appointed by the Scottish Government to make sure the rights of prisoners are upheld. Ms K2 describes the problems facing prisoners with AOD problems.

In 2018, RA contacted Barlinnie prison, and made training available to prisoners in recovery to help others in similar situations. RA have also made the RAPA available to potential candidates, including staff and ex-prisoners in recovery.

*“The guys in Barlinnie prison have lost their home. That could be their community they have known all their life. So, they may have lost ties. They may be put into a hostile environment (on release), so they have lost their sense of belonging as well. Their health is poor. If I can relate it to maybe they have a sense of shame. They are powerless within the system because they have a criminal record. Society views them as the lowest within society” (Ms K: 53 RA volunteer, and candidate for RAPA).*

#### **How would explain what you understand about stigma?**

*“...drug users are stigmatised within society. There is a typical view that they are thieves, and most HIV+. They are discriminated against, very clearly discriminated against. Not only by services but also by the media. It is a very negative identity that we have put onto someone with a drug problem”.*

*“People with drug or alcohol problems are disowned by society. They don’t have a sense of belonging to society. They are social beings who need to belong. They get marginalised” (Ms K: 53 RA volunteer, and candidate for RAPA).*

### **What causes the stigma associated with drug use?**

*“I think when people see people who are clearly drug users. For instance, their appearance has changed, heroin users are quite thin. Everybody loves a scapegoat. Also, that someone with a drug problem becomes objectified. You stop seeing the human being, they become the ‘other’. They become an object...fuelled by misconceptions and the media, and fear” (Ms K: 53, RA volunteer, and candidate for RAPA).*

*“Universal credit is making even more people impoverished. The delays in payment. The delays will save the government money. I think everything that the government does is intentional. There is an intent behind it. Even if it’s not the policy, it will be the lack of realisation that this will impact on the individual because of the delays. If you have a lot of money. Six weeks may not mean a lot to you. But someone with nothing it is huge” (Ms K: 53, RA volunteer, and candidate for RAPA).*

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### **INTERVIEW 9: MS M**

Ms M is 63 years old and has several undisclosed Adverse Childhood Experiences. Her husband regularly physically and mentally abused her. Constantly estranged, and with several attempts at reconciliation, he left. He returned on some occasions, and left small amounts of money, which Ms M used to support her daughters two children. She has never used drugs and reports only occasional drinking. Her health suffered when she was diagnosed with HIV and attends Monkland’s hospital for treatment for complications arising from HIV. She was recently diagnosed as having suffered a mild stroke. Her husband never disclosed his HIV status to Ms M, and this betrayal has led to severe depression and anxiety. A neighbour contacted the DWP and informed them that her estranged husband was living with her and supporting her, which Ms M denied. The DWP conducted a fraud investigation, the result of which led to Ms M being sanctioned and losing access to benefits. She is in arrears with rent and council tax. Her health continues to deteriorate. At interview, Ms M was depressed, almost unresponsive, and the

interview lasted over 90 minutes. Ms M has been supported by RA in making and keeping appointments with DWP and has had some benefits reinstated.

**Can you define vulnerability?**

*“I don’t ken how to answer that...Someone like myself who has suffered beatings, and rape” (Ms. M, 63, RA client).*

**Can you tell me about your experience with DWP?**

*“My experience was awful, they accused me of having two slices of the cake, they were basically accusing me of stuff that was not going on, and I was not able to put my side of my health problems. They (DWP) made me feel as if I was a bad person. The way they accused me, getting me to walk in front of everybody during the assessment. Sniggering at me walking out of the door” (Ms. M, 63, RA client).*

*“That time with the DWP, it took three years for it all to go to court. I was just shattered (breaks down crying). (I was told that) the best thing you can do is make a deal, I had to say I was guilty. I felt pressured to make this deal. I know it was the wrong thing to think...It was a horrible, horrible experience. That day sitting in the court, and all the people coming in to be picked for the jury, it was just horrible, the way they looked at me, like they were disgusted with me. There were people there from my home town who knew me” (Ms. M, 63, RA client).*

**Can you tell me about your experiences of receiving treatment?**

*“Years ago, when I was going through, there is stuff that I can't even speak about of what’s happened to me. In Monklands they have been absolutely amazing, brilliant. The doctor there was amazing. He was very angry about how I was treated by the DWP. He made me feel stronger and better about myself, but that was hard due to the bad experiences I have been through” (Ms. M, 63, RA client).*

**What do RA help you with that is essential to your well-being?**

*“I don’t know, it’s just that they are there for me. Support workers take me to appointments and stuff like that, that’s really good for me. Basically, going to hospital, if I need to go to DWP for an assessment this Friday, I am absolutely dreading it. It makes me feel bad about myself. They (DWP) will judge me unfairly. Based on how they treated me before”.*

*"I am struggling right now. I got through a letter for a TV licence, and I just broke down in tears, and that someone will come to my house. That makes me feel unwell like".*

### **How has RA helped you?**

*"They have been absolutely brilliant with me. My rights, they have helped me get a wee bit more money off them. Its only £30 like, but thirty pound is thirty pounds. My money was stopped for nearly 18 months. I found out about RA when I was attending Monklands. I have to go there due to my HIV. They are limited to what medication they can give me, due to really bad side effects. My status is something I have tried to learn to deal with it. It has taken me a long time to accept my diagnosis. I feel judged, when they know about my HIV. Well my oldest lad has totally disowned me because of it. People don't understand. They don't know how it happened and why I got it". I don't want to go to the dentist. Because of my HIV. I feel dirty, and they would need to know about my HIV"*

*"HIV? I just feel as if it is a life sentence. Basically, I just ask myself how this could have happened. I think what hurts the most about it, is that I never got the luxury of keeping myself safe, the fact that it was hidden from me hurts the most, I did not get the option of protecting myself. My husband (gave me HIV) he knew he had it and never told me. That hurt a lot".*

*"...my own daughter in law told me I deserve all I got. Now I have 2 great grandsons and I can't even see them. Now I am a bad person. I don't want to be judged as a bad person, I've never been a bad person".*

*"I know people can be well with HIV, but I am not one of them. I feel like I am judged for that as well. Especially when I am at DWP, I feel like be I will be judged. Oh, they will say that she's well dressed, but what does that mean? My daughter dresses me for the appointment. Most of the time I just take to my bed and I am never out of my jammies. People just do not understand about mental health".*

*"In the first assessment for my PIP, I was driving, but I had this growth on my brain, and I should not have been driving! But what they say (DWP) about how you are dressed, they don't know who that person is inside. (Ms. M, 63, RA client).*

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## INTERVIEW 10: MR. S

Mr S was a young offender at 17 and given a life sentence. He served 24 years in prison. He struggled with alcohol drugs and poor mental health prior to his prison sentence. He is now a controlled drinker and uses no illegal drugs. He is in regular contact with a psychologist for help with anxiety. He is out of prison on licence and must remain in contact with a Parole Officer for the rest of his life. Now 42, he describes how on leaving prison that he struggled to get the support he needed to look after himself, his accommodation, and dealing with Local Authority Housing and the DWP. He was given accommodation on his release from prison and struggled to have repairs carried out on his flat after his upstairs neighbour who was alcohol dependent and rented privately, ignored all requests and responsibilities in paying for his part of the repairs, after his boiler leaked flooding Mr S residence, and damaging his ceiling and walls. The Local Authority Housing department refused to carry out the repairs, due to the private let not accepting responsibility for the damage. Mr S reports several frustrating months of asking for help from the Local Authority Housing Department, and his Parole Officer. He finally received help from Citizens Advice. At a medical assessment at DWP his benefits were stopped for a month, and he was put in contact with RA by CA. RA helped him with his medical assessment at DWP, his benefits were reinstated.

*“I was given a life sentence, I was in jail for 24 years. So, I never had a house before I did not know what to do. Housing told me that if I see any repairs write them down in a list and let them know. But the person living above me had a private let. His boiler broke and flooded and caused massive damage in my ceilings and walls. So that meant that my repairs could not get done, the guy upstairs was just blanking everything, not paying for anything. So, nothing was done for 2 years. I was starting to get a bit frustrated, and I did not want to get back into trouble again. So, I went to RA. I did not know how to go about getting this done. I was getting frustrated. So, I did not want to get angry, and go down my previous path” (Mr S, 42 RA client).*

### **Can you define quality of life in your community?**

*“It depends. Having a roof over their head, a place to sleep, and having food, something to eat. People take this for granted obviously, but some people don’t have that. If you don’t have any of these things, then you are not in a good place. It does not take much to be content and have in your own head a QoL. But having choices having freedom, having the ability to say I don’t want*



*to do that today, or I want to do that today, that's freedom, that's choice, that is quality of life" (Mr S, 42 RA client)*

*"In a community, if you are a drug user a junkie, then that is at the forefront of your mind. You do not give a fuck about your community. The community sees that that you do not give a fuck about putting your bin out, or keeping your house clean, or keeping your dog quiet, or paying bills. The community sees that. The community is not blind to what is going on around them. If you have a raging drug habit, that's all that is on your mind. You do not give a fuck. All of that is on the back burner, if you're a junkie. In a family environment, QoL, if drugs are there, then QoL so not a factor in that family. So, if drugs are there, that has an impact on the family, on kids QoL" (Mr S, 42 RA client)*

### **What were your Experiences of DWP?**

*"Terrible... the trouble I was having with my benefits, they took me off my benefits which then had a knock-on effect on my housing, and it was just getting out of order, going here there and everywhere, being passed from pillar to post, different people in the same building. I am on ESA. I don't know it's like you go to a thing in Cadogan street, Glasgow, and you get a certain amount of points and I got one less point that I needed, and it just caused chaos, my housing (benefit) stopped, has a knock on effect ... they give you points for things, and then ask another question (and) you don't get points, its bizarre" (Mr S, 42 RA client)*

### **How long were you without any money to live?**

*"After I had been taken off benefits, this is when I found out who was helpful, and had the correct advice, and who didn't know. I went to my parole officer, they sent me to the Jobcentre, to ask for something I was not meant to ask for, and then I was put on jobseekers (allowance), until that was all sorted out. I explained all of this to the jobcentre staff, she (asked me) have you ever been taken off benefits before? I said no, she said there is a one-time thing where you phone the DWP, and say I am on ESA and I wish to be kept on it until my appeal is heard. So, I then went and did that and said it exactly the way I was told to. I then said this to the DWP guy on the phone, and he just laughed at me, and he said, "tell people on GSA not to advise people on ESA". I then went to CA and told her all about this. And I was told that I was going to be without any money for a month purely by following that advice and asking to be kept*

*on ESA while my appeal was being heard, and that was wrong. I only survived through help from my sisters. But if I had nobody, it would have been different”.*

*“I had to go for a medical at DWP, and RA went with me. I goes in and it’s not easy going into these things when you are heavily scrutinised. You go into a counter, give them your letter, and then you are told to go wait in a corridor outside an office. There is also a waiting place which is on the ground floor, it’s all glass fronted, and everybody in Argyll Street can see you sitting waiting there”.*

*“At the assessment, there is one person behind a desk, a woman, there is a certain repertoire you need to spit out. They ask you to do several movements, some of which I can do, some I can’t. I have a steel plate in my thumb, an injury cut the tendons in my thumb”.*

#### **Are you partially disabled?**

*“Well this is the thing the assessor was holding my hand and trying to find out if I had full movement, but I don’t. And RA are trying to fill in all the blanks that they are not assessing, you know advocating for me...But they (DWP) don’t assess your mental health. I see a psychologist, because I am struggling to adapt to life outside” (Mr S, 42 RA client)*

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#### **INTERVIEW 11: MS. B**

Ms B is 51, divorced and has two children, who are not dependent on her. After an illness, she had an operation on her brain which has left her significantly disabled. She suffers from severe memory loss. Presenting as very vulnerable, she has struggled with debt after lending money to neighbours and distant family members who did not repay her. Her medical conditions means that she requires advocacy from RA when in contact with DWP.

*“I was quite vulnerable a few years ago giving out money and still not receiving it, even after a long time. I had a lot of money around about the time of my divorce. I felt myself (to be) really vulnerable then” (Ms B 51, RA client).*

### **Can you tell me about your experiences of treatment services?**

*“Treatment when I was ill? The treatment I had was a ten-and-a-half-hour operation to get my brain tumour taken out. It is a returnable brain tumour ... I still go the Beaston Hospital every six months. That’s when I started to go downhill. I didn’t want to go out. I didn’t want people to know. I didn’t want people to feel sorry for me. I’m not that sort of person. It came to the point that I would keep away from anyone. I ended up feeling lower and lower and then I came here” (Ms B 51, RA client).*

### **What was it that brought you to RA? Was it an issue with DWP?**

*“Yeah, it came to the point that I was only getting sick money. It was a pittance a week to keep me and my kids...I came here, and one phone call was made. The next week another phone call was made, and I got my money. It was put up. It was great. That was a worry as well. Not getting money in because I was off sick from my work and was on no sick pay. I was told that that it was rubbish. So, I came here. I was finding it difficult to survive” (Ms B 51, RA client).*

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#### **INTERVIEW 13: MS. K**

Ms K is 61, is a widow who served over 20 years in the Army. Her husband also served in the Army and was a police officer until he retired. Ms K suffers from PTSD, due to her life time of physical, emotional and mental abuse from her husband, who was a problem drinker. Ms K uses no alcohol or illegal drugs. She suffers from extreme anxiety related to her PTSD.

After losing benefits related to a medical assessment conducted by the DWP, Ms K struggled to pay her rent, her council tax, and purchase food. She has a very small pension related to her former employment. She reports being ill-treated by the DWP.

At present while in receipt of advocacy support from RA, she is now in contact with Veterans First, Poppy Scotland and Erskine Hospital to receive counselling help for PTSD.

*“There is nothing wrong what me physically, it’s my mental health. SAMH, and Poppy Scotland were paying for counselling for me for PTSD. None of that was available to me through my GP. I can't take anti-depressants, as I can't*

*cope with them. They give me headaches. I am vulnerable, and when I lived in England, I tried to take my own life” (Ms K, 61, RA client)*

*“In my last council house, I had drug dealers living above me. It was shocking, there were constant ambulances, undercover police officers, constant arrests I asked the council to help me, and they told me that it would take months. They did move me, and I’m in a one-bedroom house, I just sit there on my own staring into space” (Ms K, 61, RA client)*

*“Firstly, I was getting PIP, and I went into Motherwell, because I could not get to Glasgow, and I saw a young girl who thought I was stupid. I should have been there with someone from CA. My appointment was at nine am, and I was there for 8.45. I was in after 9.15, she said I can give you a couple of websites to look at. I said I did not have a computer. She gave me zero points. When I got that (letter) I phoned DWP, and she told me that I had saw the nurse, I asked if she was a mental health nurse, she said no but she has training. I took this to appeal after seeing CA. They had a welfare rights officer, they got in touch, I went to see her, and I was put on ESA. Once they cut my PIP... they (Housing Association) wanted to take full council tax, and I had nothing to live on. I was referred to RA, they took me into Glasgow.*

*When I went to get the PIP, they had written that I was 'well kept'. Meaning that I was well dressed. (DWP) stated that I was articulate, but what they write and say about you, you have no control over. She did not know that I spent most of my time in bed due to my mental ill health. Why did she say I was well-kept? She knows nothing about me! (Ms K, 61, RA client)*

*“Nobody listens to you in these places, all they do is sit and tick boxes. When you ring DWP, you are speaking to people in a call centre in England. And they do not have a clue about Scottish services” (Ms K, 61, RA client)*

*“When I appealed against losing my PIP, the DWP said they had lost the paperwork. Luckily CA had kept records and sent it to them. The appeal process took three months, and I had nothing to live on, after paying rent and council tax. But I did get my rent and council tax suspended eventually while the appeal for my benefits was ongoing. RA did that for me” (Ms K, 61, RA client).*

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#### INTERVIEW 14: MS. P

Ms P has struggled with mental health problems throughout her life. She reports that she self-medicated with several illegal drugs in addition to using alcohol. She has now been abstinent for 2 years, and regularly attends NA and AA, 12 step self-help programmes. She was in receipt of Jobseekers allowance and was told she had to take 16 hours employment or lose benefits. After travel to the company to work, and paying her rent and council tax, Ms P was significantly in debt and asked RA for help. She has asked not to receive Universal Credit, due to her issues with the problematic use of AOD. She describes herself as vulnerable, requiring a great deal of support when engaging with DWP, Housing, and treatment providers.

*“My addiction was really bad, my kids were taken off me, and I just started using more; Social Work got involved and things just snowballed, SW took him off me. I was grieving the loss of my son who was taken off me. SW though had every right to take my kids off me though, as I could not feed them, as I would just buy drugs” (Ms P, RA Client)*

*“When I went to see my kids, at the home where they were, the police were called, and they said they would lift (arrest) me. They treated me like an animal” (Ms P, RA Client)*

*“I have used foodbanks before (when) I had no money, nothing. I was really like a dead woman walking. The foodbank is in a church...They are just getting busier and busier now. (Ms P, RA Client)*

*“Addicts feel as if addiction workers are in control of your life, if you don't turn up for an appointment, or fail to go to a chemist, they take you off your script. I felt as if SW and drug workers were in control of my life, there was a lot of resentment. They could have helped me understand my addiction. I only receive help from the fellowship, not from a CPN or addiction worker” (Ms P, RA Client)*

*“My housing officer knew of my troubles with addiction. I told them though that if I was given access to my benefits, that as I was actively using drugs, my rent would not be paid. This universal credit, (will) supposedly make people responsible, but there is not enough support out there. I don't know how to pay a bill. I find it hard to use a computer, and there is no one to help me get online. Everything is online now” (Ms P, RA Client)*

*“And right now, the Jobcentre are on my back. They are threatening to stop my money, they're saying that I have to work. When I went to the company,*

*the company informed me that I would be worse off, coming off my benefits. But they are threatening to stop my money. RA are helping me” (Ms P, RA Client)*

### **How have RA helped you?**

*“Just being there for me and never turning me away. Now they’re going to lose their funding, and that is hard...RA can identify with mental health, as they’re involved with recovery. I have to be around safe people. People need to be soft and gentle with me. Even if I have had a relapse, RA were always there for me” (Ms P, 51, RA Client)*

### **Is abstinence suitable for everyone?**

*“I think it’s for me”.*

*“The doctors diagnosed me with clinical depression as a teenager. My mother told them not to medicate me. I am glad I did not take psychiatric help. It’s hard to get out of that when you are in it. I’ve seen it with my uncle, and some of my friends, stuck on medication sitting in their house isolated” (Ms P, RA Client)*

*“I do not want anything off the doctors though, getting mood altering drugs is scary and I fear relapsing” (Ms P, RA Client)*

*“I fit in the fellowship, and I fit in here at RA. But normal people they’re just crackers. I surround myself with other addicts. I just do not fit in, I fit in with other addicts” (Ms P, RA Client)*

### **Discussion**

Mr B is physically disabled, and having had problems with AOD, and suffers from mental ill health, he became unable to cope with increasing debt.

Mr M is quiet, softly spoken, and unassertive. His difficulty in communicating with medical staff at a time when he was requiring support resulted in frustration, and he felt that he was diagnosed incorrectly with a non-specific psychiatric disorder and prescribed medication which he wishes to come off from. His vulnerability, and inability to articulate his needs, and his mental instability, resulted in accruing significant debts.

Mr T is physically disabled, and after a DWP assessment put on Jobseekers allowance. His experiences with DWP impacted on his mental health, resulting in severe depression. Debts began to accrue, and he contemplated suicide on several occasions.

Mr R, a problem AOD user, is a single parent, and after having his daughter taken into care by Social Work, became depressed, and being unable to find regular full-time employment, accrued significant debts.

Ms K2 a RA volunteer, works in a remand prison, highlights the difficulties problematic AOD users, and dual diagnosed prisoners have after leaving prison.

Ms M suffers from PTSD, and after many years of abuse, and contracting HIV from her former partner, accrued significant debts after DWP found her guilty of being in receipt of monies from her estranged partner, which she denied. This led to her mental health deteriorating, difficulties in attending appointments, and DWP applying sanctions on benefits significantly increasing rent arrears and other debts.

Mr S was a problem AOD user, with severe mental ill health who after serving a life sentence (released on a life license) was unable to liaise with any government agency without support. He accrued significant debts.

Ms B suffered a brain injury and was left unable to work. She accrued significant debts and was unable to attend DWP without advocacy support.

Ms K suffers from PTSD linked to her military service and having endured trauma from her ex-husband. She was further traumatised by her experiences with DWP and was put into severe financial hardship after losing access to benefits. She is unable to liaise with DWP without advocacy support.

Ms P has struggled with problem AOD use and mental ill health throughout her life. Contact with DWP, treatment agencies, and social work, all impacted negatively on her physical and mental health. After accruing significant debts, she sought advocacy support.

These ten case studies indicate the common experiences of many of the clients attending RA services. As rights bearers, all were unaware of their rights, and as duty bearers, many of the services set up to provide services to them, failed them.

The UNDHR 1948 set out 30 Articles, and the ICEHR sets out 31 articles related to rights, including the rights to health. In these case studies we have indicated that each of the following articles were not adhered to by services and agencies.

Article 5.

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

Article 7.

All are equal before the law and are entitled without any discrimination to equal protection of the law.

Article 12.

No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation.

Article 22.

Everyone, as a member of society, has the right to social security and is entitled to realization...and the free development of his personality.

Article 25.

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, and housing and medical care and necessary social services.



## THEMATIC ANALYSIS OF INTERVIEWS

The following themes were identified using adaptive coding from interview transcripts conducted with RA trainers, Service providers, RA volunteers, and RAPA graduates (Neale et al., 2015).

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### VULNERABLE CLIENT GROUPS

The report to the UN by the Special Rapporteur acknowledge that persons who use drugs are:

*“... a highly stigmatized and criminalized population whose experience of health-care is often one of humiliation, punishment and cruelty...In some cases the laws specifically single out the status of a drug user as a stand-alone basis for depriving someone of custody or other parental rights. Use of drug registries – where people who use drugs are identified and listed by police and health-care workers, and their civil rights curtailed – are violations of patient confidentiality (ibid) that lead to further ill-treatment by health providers” (Mendez, j., 2013, p. 17).*

Mr D a RA trainer suggests a combination of societal reaction in the form of stigma leads to discrimination. In addition, contact with existing services increases vulnerability of dual diagnosed individuals, and a corresponding inability to cope with the myriad of institutions that are there to provide services:

*“In my work experience since the mid 1980’s, vulnerable means to me people who do not necessarily have the skills to navigate their society, meet with and deal with organs of government, health services, the Criminal Justice System, and Social Work” (Mr D Trainer, 51)*

Miss K a RA volunteer goes on to suggest that added to the definition of vulnerable is the client’s inability to comprehend what is available on terms of help for them:

*“...probably a lot of the people we see who are extremely vulnerable is because they have no idea what’s available” (Ms K volunteer, 24).*

The notion of the addict as undeserving was commonly reported in the qualitative interviews. Ms K a RA volunteer who successfully completed the RAPA states that problematic AOD users can be considered as underserving of treatment, help and support:

*“It’s an easy client group to say, ‘you can just wait’, to fob off, for more deserving people. They are not an attractive client group. They are not people*

*with learning disabilities or physical difficulties... they are people we don't feel sorry for. (Others say) well it's your choice, is your decisions that made this, you should just stop (taking drugs), although people don't say that this is the kind of attitude that exists, that is there... they (vulnerable clients and AOD users) get blamed for a lot of the things going on in their lives that they are not to blame for, they are (considered to be) less deserving" (Ms K volunteer, 24).*

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## STIGMA AND DISCRIMINATION: SERVICE PROVISION

Miss K explains how vulnerable individuals find it difficult to secure access to health and treatment services:

*"So, it's like you don't turn up this day for your methadone script you're not getting it, or if you are on a methadone script so we are not letting you register with this GP, or if you don't have ID, you're not getting registered with a GP. So, a multitude of things which cannot possibly be helped which they then get punished for ... (Ms K volunteer, 24).*

*"These people are exploited by the state, 100% I think that the client group I work with they don't know the system they don't know the workings... when a Doctor or a professional worker say, 'you can't register here', they don't question it...they (practice receptionists) know that this is wrong and that the clients are not going to make much fuss about it and then it's up to us to make a fuss about it..." (Ms K volunteer, 24).*

Ms K a RA volunteer highlights how accessing the right to health is commonly denied to AOD users.

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## RA CLIENTS

Mr D when asked to describe the typical client attending RA drop in services indicates that financial poverty, after losing employment or benefits are prime drivers of first contact with RA:

*"I would say that a good third to 50% of the people we met over the last year are actually out with traditional services. When we come into contact with them, they have a range of needs. (A) primary need when they first contact us, it's about hand to mouth survival, finance, social security..." (Mr D Trainer, 51).*

Mr D summarises that current definitions of vulnerability do not capture the lived experience of the client group attending the RA service. Mr D explains the typical RA client is extremely vulnerable, mainly due to having lost access to benefits. He explains:

*“there is not one client who has made contact with us that (The DWP) was not their primary reason for contacting us, it led by the monetary side of their life, transfer from DLA or PIP, or DLA to job seeker allowance, their status..., peoples experience have been negative, unpleasant to the point that we talk about early death... there are 5 females (pre candidate clients of RA) I can think of who’s experiences of Social Security system (experiencing) the ‘medical’ assessment required by DWP has made them more vulnerable, more at risk. They have said that if it was not for you, we would be dead... I don’t know how this could be more succinct ...” (Mr D Trainer, 51).*

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## QUALITY OF LIFE

Ms K, a RA volunteer and successful RAPA graduate helpfully defines how QoL can be conceptualised in relation to the health of vulnerable clients:

*“...to have a good QOL you need to be able to access health care, access housing, you need to have a good social group around you, access to benefits, of what you need. A lot of people don’t have a house, a lot struggle to access benefits, don’t have great health and are penalised in the health care system...” (Ms K volunteer, 24).*

QoL was often defined as a lack of wealth linked to the postcode areas in which a person resides:

*“I think fundamentally QoL if applied almost universally each of us should have an opportunity to participate, be able to take part in civil society to have an equal opportunity to participate, in health and wealth, but equally I am aware of divisions in our society based on socio economic status, economic inequality based on area where people are brought up...” (Mr D Trainer, 51)*

In linking QoL to access to health care Mr D describes the situation as a postcode lottery, but importantly that perceptions of QoL are very much influenced by factors external to the individual.

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## WELFARE AND BENEFITS

The alteration of the language is important in defining the relationship between citizens and the State in the UK. The 'welfare' system that emerged after the Second World War described a new social compact to provide for those most in need. Welfare has been redefined as 'benefits', indicating the power of language in reframing the social compact between citizens and government. Mr D a RA trainer when asked how he understands welfare in relation to vulnerable clients' states:

*"Welfare for me harks back to the end of the World War 2 and the creation of the NHS and the creation of social security and (now) we have totally forgot health and welfare, from cradle to grave, as it was about not allowing the social and political and economic circumstances to ever arise again in our country. The set of conditions that led to the Second World War happening...tens of thousands of people who lost their lives. The ordinary working population, the non-combatants, non-militia. When I think of QoL linking that minimum standard of QoL, it (welfare) was to support people in a time of need... now today we have regressed. People don't say social security or welfare anymore they say benefits. We have lost our raison d'être for the setting up of welfare..." (Mr D Trainer, 51).*

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## AOD USE MENTAL ILLNESS AND VULNERABILITY

Co-morbidity is a term used in medicine, which describes the interactions of two or more medical conditions on the functioning of individuals. While highly medicalised, the term is often used interchangeably with dual diagnosis. The extant literature highlights the significant cross over between both groups of co-existing disorders with, 50-75% of mental health treatment seeking population and 75% of substance use seeking populations (British Psychological Society, 2016). In highlighting some of the difficulties in providing services to people with a dual diagnosis Mr DC states that:

*"People with addiction problems often have mental health problems. The research also tell us that and then we establish services that won't talk to each other that you are in danger of creating split personalities in the people we are supposed to be helping. But we are creating a system were people have to behave in one way to go to that service and then behave in another way to go*

*to this service. And there is a natural expectation that these two services will talk to each other. But this never happens” (Mr DC, Service Provider)*

The inability of the NHS and drugs services to work together was commonly reported by the majority of participants interviewed for this study. Ms K explains why service users do not engage with services succinctly stating:

*“...they (AOD users) are so heavily judged, and I would say penalised for their addictions and their mental health by the health care system. They are all so scunnered by it...they don’t want to be involved any more with GP’s or any of these addiction teams because of the way they have been treated. They just don’t want to engage with them basically” (Ms K volunteer, 24).*

As the science underpinning addiction is less clear than that underpinning the diagnosis and treatment of mental ill health, addiction diagnostic criterion are more difficult to recognise, and symptoms more difficult to treat. Ms K indicates that while multi agency working is considered a policy priority in Scotland, in practice this is fraught with difficulty:

*“So, someone has a mental health condition, everybody rushes to help and if they have a condition like Schizophrenia they say here take these tablets and you’re going to get better. With addictions well that’s not science and they (NHS and Addictions teams) don’t like working together...They don’t like working together (the NHS) work with people with mental health problems; mental health is seen a more deserving, it’s not great trying to get them working together” (Ms K volunteer, 24).*

Mr DC explains why he believes that rights-based advocacy can help remove some of the barriers that prevent service users understanding their rights:

*“... It is that artificial separation of people for the benefit of organising service structures that is removing people’s rights” (Mr DC, Service Provider).*

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## DUTY BEARERS: NEEDS BASED SERVICES

In discussing why current needs or issue-based services fail service users, Mr D states that:

*“(With) national organisations that are there to help (AOD users) there is cracking big sign that says ‘zero accountability’ there is zero culpability...That*

*is what I see in our society, there is no accountability. If you have tasked people with reducing inequality... nobody wants to fail to meet government targets, and there is something amiss. The bystander effect where everyone assumes that someone else expects someone else to do something..." (Mr D Trainer, 51)*

Mr D states that a culture of meeting targets underpins drug policy, service activity and provision. A requirement to produce statistics to satisfy funding bodies so the service is meeting targets has unintended consequences. In addition, Mr D mentions the bystander effect, where everyone else assumes that someone else has a duty and a responsibility to address complex needs of vulnerable individuals.

Mr D also offers an explanation why addiction cannot be considered to be a protected characteristic akin to mental ill health. There is existing legislation regards equalities and mental health. However, addiction is not considered a protected characteristic in law. He explains the challenges in providing s service to AOD users and dual diagnosed clients:

*"I think bringing human rights and equality into primarily mental health and addiction population, I did not think it would be as challenging... of addiction why was it taken out of the Disability and Equalities Act, well because Parliament reigns supreme..." (Mr D Trainer, 51)*

Seeking evidence of why the UK parliament had not included addiction in the Equality Act 2010. RA were informed that:

'Parliament is supreme and (...) is not bound by any particular school of thought and used its prerogative to decide that addiction in itself will not be protected under the Equality Act' (Source RA private email, 2018).

Mr D suggest that there are many individuals who provide services who fail to recognise that problem AOD users have rights, and that they as 'duty bearers' are accountable not only to government, but also to the rights bears as service users. He explains:

*"I can quote you a service manager I have spoken to at a training event I attended, he said these people (drug users) do not have human rights. Is that a one off in my experience? I would say no..." (Mr D Trainer, 51).*

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## RIGHTS-BASED ADVOCACY

In 2004 the Scottish Executive Effective Interventions Unit published *Advocacy for Drug Users: A Guide*. The Guide posed the question 'Could advocacy be useful for drug users?' In response to this the report states:

*'Evidence shows that people who have drug misuse problems will, in many cases, have a range of other difficulties in their lives. These difficulties include problems with housing, family relationships, employment, offending behaviour and debt...'* (EIU, 2004).

In explain the approach taken by RA, Mr DC suggests that:

*"Yes, we are talking about human rights and that applies to everyone. So, what they are doing here at Reach, they are working with human beings. They are not working with addicts. They are acknowledging that many of the people who come here may have had complex needs or multi-dimensional problems, but they are not labelling them by that..."* (Mr DC, Service Provider).

When asked to explain the role of RA as a service, and as a provider of services, Mr DC states:

*"Until I came here, I had never heard anyone talk about the European Convention on Human Rights in the addiction field. You would hear about it at university but not in the addiction field... (It is) ...a genuinely humane and person-centred approach with people but removing all labels, (RA) are dealing with people and not service users. Not clients but dealing with people"* (Mr DC, Service Provider).

Mr D explains why RA are able to understand the specific needs of the clients who they offer advocacy to:

*"...we work with the person, where we pick up with DWP because ... we are an observer and a recorder of the situation, (and) there is a very rapid positive outcome for that person and their relationship to the DWP. I can say that is down to us using human rights legislation. We have used the Mental Health Act once or twice, it's about just being there and drawing attention to it (discrimination)..."*

*"...the Social Security system itself has time triggers, so if we were (operating) as traditional issue-based service we would never have witnessed what is truly happening, only because we work with the person over many issues, as (existing) services address only one issue...because of how issues-based*

*services are traditionally funded, they miss all these issues, and we don't, because we deal with the whole person" (Mr D Trainer, 51).*

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## FAILURES OF DUTY BEARERS

Mr D puts forward the idea that as the general public and politicians are bombarded by media stories of stereotypical addicts, benefits scroungers, and work-shy hedonistic addicts, that it is understandable why the public react to drug users as they do. That said, echoing Maia Szalavitz he explains that:

*"If I look at media I do not think there is any doubt that they are the perpetrators of discrimination, I do not see the media being held to account...the gay community LGBT, black community, women's emancipation, the media had to learn how to deal with all of that, but when it comes to the unemployed, dual diagnosed, drug users, I see no such vanguard of people, wringing their hands or any public outcry, or anyone advocating for these people. It (discrimination) is so entrenched" (Mr D Trainer, 51).*

The special rapporteur recommends that to reduce the risk of inhumane degrading and humiliation of vulnerable individuals including drug users that there has to be:

*"appropriate human rights education and information to healthcare personnel on the prohibition of torture and ill-treatment and the existence, extent, severity and consequences of various situations amounting to torture and cruel, inhuman or degrading treatment or punishment; and promote a culture of respect for human integrity and dignity, respect for diversity and the elimination of attitudes of pathologizing and homophobia. Train doctors, judges, prosecutors and police on the standards regarding free and informed consent..." (UNODC, 2010).*

It is clear that many services understand the need for advocacy, however there is much misunderstanding about what a rights-based service should provide. It was due to the lack of understanding of both rights bearers and duty bearers that RA undertook to create the RAPA.



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## RAPA TRAINING CONTENT

When RA were deciding what to include in the RAPA training, there were several decisions that had to be made. It was acknowledged that it was not targeting NHS or health professional, social workers, or even drug workers per se. Initially it was aimed at providing educational experiences and a route into employment for people with lived experience. The decisions on what the RAPA would include and to whom it was targeted formed the basis of much of the interview discussion we had with both RA trainers.

Asked about the content of the RAPA Mr D explains how they decided on what would be included in the SCQF level 7 qualification:

*“So, our challenge was how do we make something so broad into something that is manageable in terms of participation, but in line with SQA, but not dilute it... So, we focused on key areas, professional and inter-professional practice, information gathering, boundaries, working with the client, setting goals and aims, working with other agencies. Record keeping is a fundamental, without good records, without good recording practice we lead ourselves into potentially muddy waters. (Mr D Trainer, 51)*

The RA advocacy trainers were asked who the RPA was to be targeted to. Mr J explained that:

*“You cannot go wrong with human rights...so it was not just for people in recovery. We used the Equalities Act, so that the (RAPA) award is for everyone. We were also thinking about franchising the award that this could keep RA going, and we would become a charity. We did not just want it to be about recovery or addiction. So that anyone could attend, do the award and know about human rights” (Mr J, RA Trainer).*

Explaining the low numbers of Candidates successfully completing the RAPA Mr D explains:

*“There was an obvious deficit in educational and social skills in the population I worked with so when we first developed the (RAPA) model, it was a three-stage development model...Stage 3 was about (stable recovery) ...to be able to do the award and become an advocate worker” (Mr D, RA Trainer, 51).*

*“But we cannot let people who have not met stage 1 and 2 to enrol on the award...we tried to adhere to our spirit to provide meaningful experiences for people in recovery... but in terms of our funding we could not do what we do to have these people go through the three stages in their (recovery)*

*development. So, it's been difficult on setting out what we wanted to achieve... but we have stayed true to our original ideology...But society, the funders, the government (they) do not see the whole person, they only see someone in recovery... it's been difficult" (Mr D Trainer, 51)*

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## FUNDING REACH ADVOCACY

On the issue of how and in what way RA were funded, they had this to say:

*"But currently our experience leads us to believe, and my colleague believes this, is that we do not fund the person (the government, and other funding bodies) fund a problem... so when we were thinking of getting candidates through the 3 stages, this sit outside the current funding model. It sits outside the current models we have on recovery, we have...so we at RA experienced these challenges....so government bodies fund issues, so services are allowed to state well we work with addiction, but we don't do mental health and vice versa... (Mr J, RA Trainer, 51).*

There were issue about what could and should be funded. Naturally the BLF had to think of success criterion, however there were issues about who would be ready as a candidate to undertake the award:

*"When we worked with the BLF they did not want stage 1 and stage 2, they only wanted stage 3, people who were in recovery maintenance (stage 3) who went through the award... what they did not understand was people early in their recovery (are not ready) to go through stage 3 and do the RAPA award..." (Mr D Trainer, 51).*

Mr DC further elaborates on the difficulty in achieving stage 3 and stable recovery. He acknowledges that recovery was challenging from many individuals for several reasons, cuts to funding in addiction service provision, reliance on self-help recovery groups to deal with individuals in crisis, and that it takes a considerable amount of time for vulnerable individuals to be able to work with others to begin to recover. He explains:

*"...there is a big journey from being treated in safety at the point of crisis to getting to the point where they (AOD problem users) can manage on fellowship meetings. All that support, a lot of funders think you can do it in 12 weeks, but you know you are lucky if someone is actually opening up to you after six months. There is a whole lot of trust there...There are layers of trust.*

*It takes time to articulate issues and address those many issues. We want to deal with all their complex issues at the same time. If I was in their shoes I would be dealing with the issues one at a time until I feel safe” (Mr DC, Service Provider).*

## DISCUSSION

Part one of this evaluation set out the context in which RA operate as a rights-based advocacy service and explored how vulnerability is defined in the context of recovery.

We evaluated the impact of the RA level 7 SCQF award on candidates (participants in the RA training) levels of therapeutic commitment using the adapted AAPPQ (Shaw et al., administering the AAPPQ to candidates’ pre and post training. While the number of RAPA candidates who completed the award were small at the time of evaluation (N=10), there were significant increases in therapeutic commitment post RAPA training, indicating that the RAPA is effective.

We evaluated the suitability of using the WHO QoL questionnaire on individuals in recovery and discovered that the longer the candidates and pre-candidates (RA clients) were in recovery, broadly, the higher the scores in each of the 6 domains in the WHOQoL-100. This has allowed us to introduce a new term into the recovery lexicon, that of ‘recovery oriented QoL’. However, we also note that the numbers completing this 100-item questionnaire were low (n=28), and that more research is required.

The overarching aim of this evaluation of an independent advocacy training service provider, and independent rights-based advocacy service was to examine the impact of RAPA<sup>20</sup> training, document the QoL of candidates and clients using the advocacy service in the context of recovery. Our findings suggest that:

- 1 An inclusive rights-based approach to advocacy in the context of recovery is innovative and markedly different from existing needs and issues-based service provision for problem AOD users and dual diagnosed individuals.
- 2 Candidates successfully completing The SCQF level 7 RAPA document higher levels of therapeutic commitment using the adapted AAPPQ which indicates that the RA services staffed by individuals with lived experience can and do create education opportunities in the context of recovery using innovative and national standardised vocational education.

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<sup>20</sup> Reach Advocacy Practice Award

3 Service provision underpinned by Human Rights and lived experience of individuals in recovery, impact positively on quality of life (QoL) across the social determinants of health documented using the WHOQoL-100.

The longer a candidate is in recovery, the higher QoL mean scores. Conversely, clients attending RA, who have not maintained or achieved long term recovery have low QoL mean scores. However, after receiving intensive support from RA, the QoL of clients (pre-candidates) commonly improved.

Arguably one of the greatest achievements of Great Britain, now the UK, were the changes in the provision of the social compact between citizen and state, the NHS and the welfare system of benefits for the sick, vulnerable and those who lacked employment. The philosophy underpinning this has been systematically eroded and underfunded by successive governments since the Second World War. The uneven distribution in income and wealth has been widening for decades, and the poor and the most vulnerable suffer poor health, life expectancy, and at greater risk of problematic AOD use, mental ill health, and early death.

In a society that has been taught to demonise, stigmatise and discriminate against users of drugs controlled by the UK Misuse of Drugs Act 1971 the individuals who are part of these socially marginalised, excluded and stigmatised populations are or perceive themselves to be marginalised, and suffer discrimination.

After more than ten years of abstinence focused drug treatment and policy, and a dramatically increasing prevalence of DRD among the most deprived communities, the rights as well as the needs of clients who are problem drugs users and who also have been attending a service in relation to mental ill health, collectively known as the dually diagnosed is required to be acknowledged and addressed by current services. The case studies presented indicates that not only are treatment services inadequate for vulnerable and marginalised individuals, there is overwhelming evidence that the overhaul of the welfare or benefits system is impacting on the mental health of the most vulnerable in negative ways.

The UN Declaration of Human Rights (1948) set out 30 articles related to the rights that all citizens in all nation states who are signatories recognise and adhere to. The case studies, and the data gathered from service providers and others indicates that breaches of human rights are common. Other areas of human rights are enshrined in the International Covenant of Economic Social and Cultural Rights (1976). This alludes to the rights to health, housing, education, and employment. All of these rights are ignored or breached when an individual is diagnosed or labelled as a problem AOD user deemed to be undeserving of welfare in the form of benefits payments, and access to adequate treatment and health services, housing, education and employment.

Investigating mistreatment in health care settings the report of the Special Rapporteur states that in relation to health care when applied to drug users is essentially interfering with the right to health.

The intention of the report was to analyse all form of mistreatment premised on or attempted to be justified based on health care policies under the common rubric of their purported justification as health care treatment, or service provision and defended by governments and workers based on administrative efficiency, behaviour modification, or medical necessity.

While it might not be the intention of services to degrade, humiliate or punish, the dignity and respect afforded to others is ignored when services are commission and provided for AOD users.

To say that we live in an unequal society belies the stark truth. We live in a society that stigmatises people who do not make 'healthy' choices, or whom others label as workshy, benefits scroungers, and foreign to our way of life. People who are affluent, in a high socio-economic position in Scotland have a greater array of life chances and have more opportunities to live a life that allows them to flourish. The affluent have not only better housing, incomes, education, they live longer and have better physical and mental health. Using just one measure of social position that of postcode area, people who live in areas which are economically and socially affluent live longer, have better physical and mental health and are very unlikely to die from drug and alcohol misuse. Such people may also have little understanding of what life is like for the poor, the marginalised, the dispossessed and the stigmatised.

We began the introduction of this report with a quotation from the ACMD from 1998:

*'Whatever the objective criteria which are employed to measure deprivation it is important to realise that what we are talking about here is a condition which at the same time will often exist as a potent, corrosive, subjective and personal experience. The mix of feelings are likely to include worthlessness and a sense of failure, powerless and the feeling of not being in control, alienation and apathy and loss of any role as stakeholder, the sense of lacking any hope of a personal way out or up and of there being no better future in sight for one's children. Deprivation is a psychological burden' (ACMD, 1998: 100).*

The ACMD note that deprivation is corrosive and is a psychological burden. Ignoring the rights of stigmatised individuals is in danger of becoming routine, and normalised. We should take note from history. Martin Niemöller (1892–1984) was a prominent Lutheran pastor in Germany. He emerged as an outspoken public foe of Adolf Hitler and spent the last seven years of Nazi rule in concentration camps. He is perhaps best remembered for his post-war words:

*“First, they came for the socialists, and I did not speak out—because I was not a socialist.*

*Then they came for the trade unionists, and I did not speak out— because I was not a trade unionist.*

*Then they came for the Jews, and I did not speak out—because I was not a Jew.*

*Then they came for me—and there was no one left to speak for me”.*

The quotation attributed to Martin Niemöller stem from his lectures during the early post-war period. While subtly different versions of the quotation exist, his point was that Germans had been complicit through their silence in the Nazi imprisonment, persecution, and murder of millions of people. While this reference to the quotation during Nazi occupation could be dismissed as hyperbole, the premise remains sound. We allow the most vulnerable in our communities to suffer stigmatisation and discrimination because we do not agree or identify with their plight. If one allows discrimination of any individual or group, then we condone the stigmatisation of all individuals and groups. Freedom for some is not freedom at all, but tyranny.

The writers of this report believe health and social inequalities that could be prevented or avoided are grossly unfair. Addressing the inequalities identified in this evaluation are not only a matter of social justice, they are a matter of life or death.

## RECOMMENDATIONS

A rights-based person-centred approach to problem AOD use and dual diagnosed individuals requires a new way to understand how to commission services. This means a move from needs-based approaches that focus on one issue such as drug and alcohol consumption, mental health, treatment compliance, or on housing that create eligibility criteria which can also be actual and perceived barriers to recovery.

A rights-based approach to problematic AOD use and dual diagnosis services requires universal services and commissioners to have as their starting point, the understanding that vulnerable and marginalised AOD users and dual diagnosed individuals present with complex and concurrent issues whilst experiencing the effects of marginalisation and discrimination.

The Social Security Bill (Scotland) 2018<sup>21</sup> describes newly devolved social security powers. Amendment 35 states that any advocacy worker working with vulnerable individuals has to abide by the advocacy service standards within a nationally recognised quality assured advocacy award by the Scottish Qualifications Authority (SQA). The RAPA provided by Reach Advocacy fits this criterion. The advocacy training standards indicate that services providing training in Advocacy should have embedded quality assured processes. The RAPA has been quality assured and assessed by the SQA and fits these criteria.

The RAPA training is underpinned by a strong focus on Human Rights aligned to The Scottish Governments Scottish National Action Plan (SNAP) and (P.A.N.E.L) principles of *Participation, Accountability, Non-Discriminatory, Empowerment, Legality*.

We recommend that service purchasers and providers acknowledge that problematic AOD users, and dually diagnosed individuals are **rights bearers**, and existing services as **duty bearers** should fully embrace Rights Based Advocacy (RBA), not in a tokenistic manner, to access government funding, but at the forefront of service provision.

#### KEY POINTS

- Independent Advocacy services require resources to build links with relevant statutory and voluntary agencies. This will lead to increased awareness of independent advocacy and benefits to service users and ensure that staff from these agencies consider referral to independent advocacy organisations.
- There is a need for assertive outreach to ensure awareness and uptake of independent advocacy amongst individuals with problem AOD use.
- Funders, including ADP's should consider creating opportunities for accessing (RAPA) training provided by RA independent advocacy. This will help improve access to independent rights-based advocacy for individuals with problem AOD use, and problems with mental ill health.

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<sup>21</sup> See the legislation at this link: <http://www.legislation.gov.uk/asp/2018/9/section/11/enacted>

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## APPENDIX 1: INTERVIEW SCHEDULE

**Clients:** Demographic information (where appropriate) age, sex, occupation, education, qualifications, area of residence

Definitions and understandings of vulnerability, in the context of recovery

Understanding of rights

Understandings of quality of life

Experiences in treatment, housing, health care and treatment, DWP.

Experiences or understanding of shame, stigma and discrimination: linked to AOD use, mental ill health, and recovery.

Understanding or experience of rights based of advocacy

**For candidates and service providers:** understanding of rights-based advocacy, exploration of roles authority, legitimacy, role support, and motivation and undemanding of vulnerable individuals and groups.

Experience or understanding of RA services

Experience of RAPA

Exploring Scotland high incidence of drink drugs related deaths and suicide

## APPENDIX 2: ADAPTED AAPPQ

Name

Organisation

Job Title

Email address

Please circle one number for each question	Strongly Agree	Agree	Disagree	Strongly Disagree
<b>Role Authority</b>				
1 I feel I have a working knowledge of advocacy & rights within health and social related problems	1	2	3	4
2 I feel I know enough about the causes of health and social problems to carry out my role advocating with vulnerable client groups	1	2	3	4
3 I feel I know enough about the physical effects of health and social problems to carry out my role when advocating with vulnerable client group	1	2	3	4
4 I feel I know enough about the psychological effects of health and social to carry out my role when advocating with vulnerable client groups	1	2	3	4
5 I feel I know enough about the factors which put people at a risk of developing health and social problems to carry out my role when advocating with vulnerable clients	1	2	3	4
6 I feel I know how to advocate clients with health and social problems over the long term	1	2	3	4
7 I feel I can appropriately advocate for my clients about their rights in relation to health and social care problems	1	2	3	4
<b>Role Legitimacy</b>				
8 I feel I have the right to ask vulnerable clients questions about their health and social care problems when necessary	1	2	3	4
9 I feel that my vulnerable clients believe I have the right to ask them questions about health and social care problems when necessary	1	2	3	4
10 I feel I have the right to ask a vulnerable client for any information that is relevant to their health and social care problems regarding right to health	1	2	3	4
11 If I feel the need when working with vulnerable client group I could easily find someone with whom I could discuss any personal difficulties that I might encounter	1	2	3	4
<b>Role Support</b>				
12 If I feel the need when working with vulnerable client group I could easily find someone who would help me clarify my professional responsibilities as an advocate practitioner	1	2	3	4
13 If I feel the need I could easily find someone who would be able to help me formulate the best approach to a vulnerable client with health and social care problems & their rights	1	2	3	4

14	I want to work with vulnerable groups	1	2	3	4
<b>Motivation</b>					
15	I feel that there is little I can do to help vulnerable clients	1	2	3	4
16	In general, I have less respect for vulnerable individuals than for most other clients I work with	1	2	3	4
17	I feel I do not have much to be proud of when working with vulnerable groups	1	2	3	4
18	At times I feel I am no good at all with vulnerable clients	1	2	3	4
19	On the whole, I am satisfied with the way I work with vulnerable clients	1	2	3	4
<b>Expectation and Satisfaction</b>					
20	In general, one can get satisfaction from working with vulnerable clients	1	2	3	4
21	In general, it is rewarding to advocate with vulnerable clients with a rights-based approach	1	2	3	4
22	In general, I feel I can understand the human rights of vulnerable clients	1	2	3	4

**RA Role adequacy**

**RL Role legitimacy**

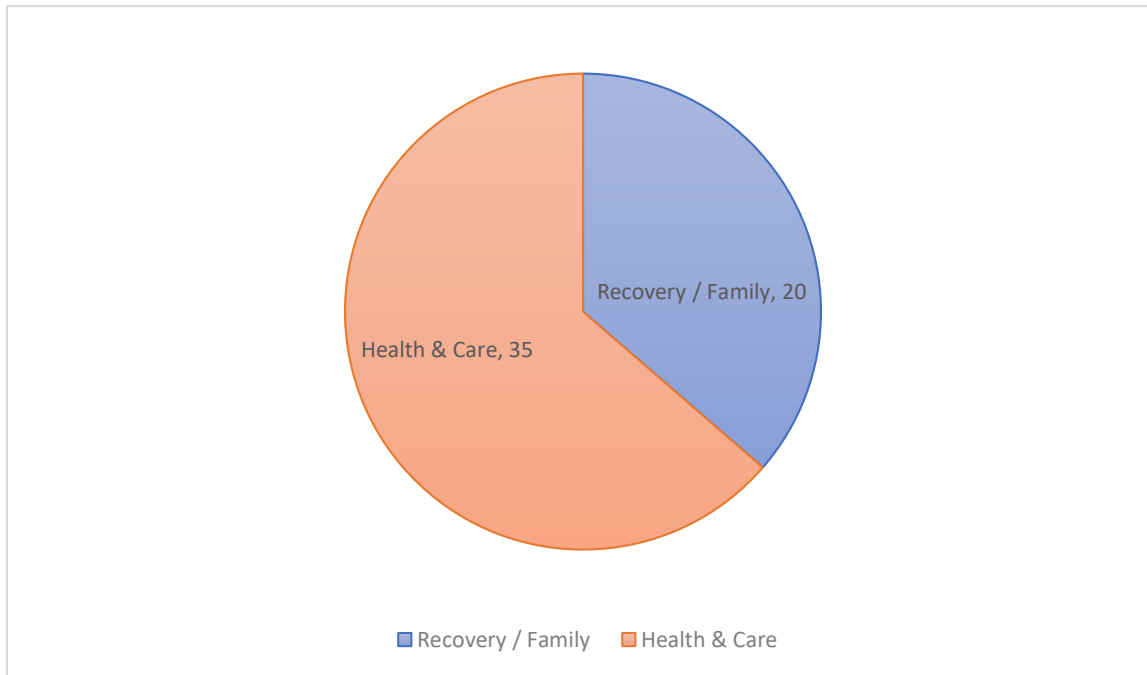
**RS Role Support**

**M Motivation**

**E & S Expectation and Satisfaction**



**REACH Advocacy Candidate interest and Potential Reach**

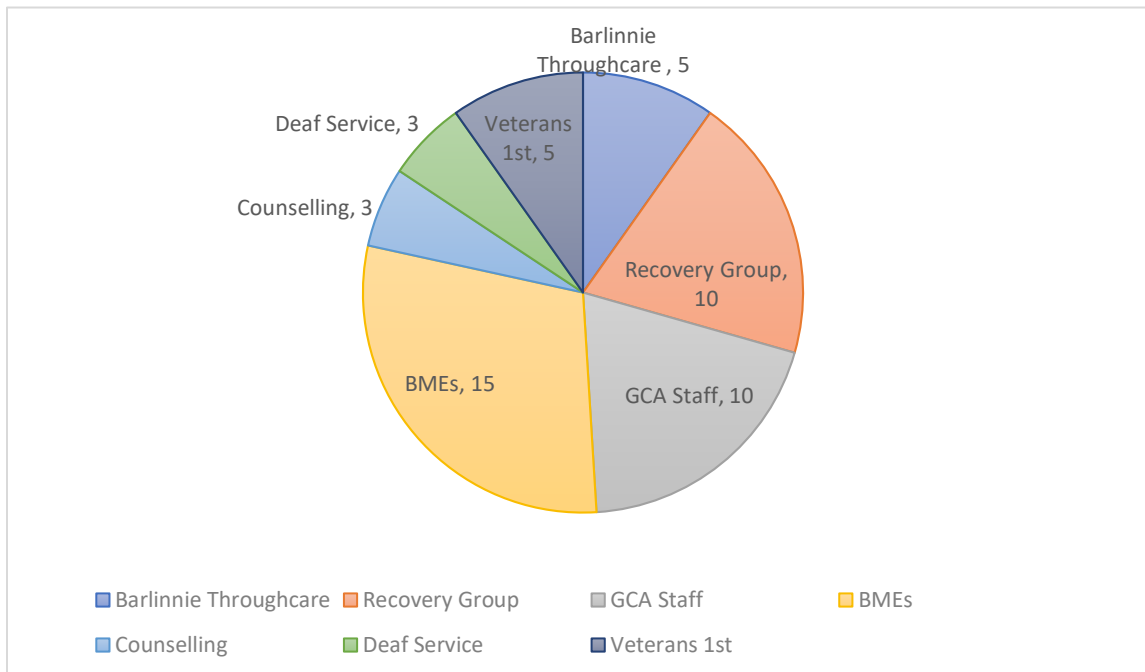


Reach have 55 individuals interested in studying for the RAPA award.

This was a mix of people in recovery/family member = 20.

People with interest of advocacy rights-based approach or work in Health & Care sector = 35

## APPENDIX 4: RA LINKS TO EXISTING SERVICES



HMP Barlinnie- Throughcare team 5+ Recovery Group 10+

GCA- Staff-10

Ethnic Minority groups-15

Veterans 1<sup>st</sup>- 5+

Local Counselling Child Abuse- 3+

Local Deaf Service- 3+

It is understood that many organisations contact RA for three primary reasons:

- 1- National Accredited Qualification
- 2- Recognition that RA have lived experience of poverty, marginalisation, and experienced in providing a service using limited resources.
- 3- A focus on Human Rights and the role it has to play in 'Rights to Health' with stigmatised individuals such as dual diagnosed and problem AOD users

**Preamble**

Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Whereas disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind, and the advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and want has been proclaimed as the highest aspiration of the common people,

Whereas it is essential, if man is not to be compelled to have recourse, as a last resort, to rebellion against tyranny and oppression, that human rights should be protected by the rule of law,

Whereas it is essential to promote the development of friendly relations between nations,

Whereas the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger freedom,

Whereas Member States have pledged themselves to achieve, in co-operation with the United Nations, the promotion of universal respect for and observance of human rights and fundamental freedoms,

Whereas a common understanding of these rights and freedoms is of the greatest importance for the full realization of this pledge,

Now, Therefore THE GENERAL ASSEMBLY proclaims THIS UNIVERSAL DECLARATION OF HUMAN RIGHTS as a common standard of achievement for all peoples and all nations, to the end that every individual and every organ of society, keeping this Declaration constantly in mind, shall strive by teaching and education to promote respect for these rights and freedoms and by progressive measures, national and international, to secure their universal and effective recognition and observance, both among the peoples of Member States themselves and among the peoples of territories under their jurisdiction.

Article 1: All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

Article 2: Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.

Article 3: Everyone has the right to life, liberty and security of person.

Article 4: No one shall be held in slavery or servitude; slavery and the slave trade shall be prohibited in all their forms.

Article 5: No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

Article 6: Everyone has the right to recognition everywhere as a person before the law.

Article 7; All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

Article 8: Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by the constitution or by law.

Article 9; No one shall be subjected to arbitrary arrest, detention or exile.

Article 10: Everyone is entitled in full equality to a fair and public hearing by an independent and impartial tribunal, in the determination of his rights and obligations and of any criminal charge against him.

Article 11(1): Everyone charged with a penal offence has the right to be presumed innocent until proved guilty according to law in a public trial at which he has had all the guarantees necessary for his defence.

(2) No one shall be held guilty of any penal offence on account of any act or omission which did not constitute a penal offence, under national or international law, at the time when it was committed. Nor shall a heavier penalty be imposed than the one that was applicable at the time the penal offence was committed.

Article 12: No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.

Article 13(1): Everyone has the right to freedom of movement and residence within the borders of each state.

(2) Everyone has the right to leave any country, including his own, and to return to his country.

Article 14(1): Everyone has the right to seek and to enjoy in other countries asylum from persecution.

(2) This right may not be invoked in the case of prosecutions genuinely arising from non-political crimes or from acts contrary to the purposes and principles of the United Nations.

Article 15(1): Everyone has the right to a nationality.

(2) No one shall be arbitrarily deprived of his nationality nor denied the right to change his nationality.

Article 16(1): Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.

(2) Marriage shall be entered into only with the free and full consent of the intending spouses.

(3) The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

Article 17(1): Everyone has the right to own property alone as well as in association with others.

(2) No one shall be arbitrarily deprived of his property.

Article 18: Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief, and freedom, either alone or in community with others and in public or private, to manifest his religion or belief in teaching, practice, worship and observance.

Article 19: Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

Article 20(1): Everyone has the right to freedom of peaceful assembly and association

(2) No one may be compelled to belong to an association.

Article 21(1): Everyone has the right to take part in the government of his country, directly or through freely chosen representatives.

(2) Everyone has the right of equal access to public service in his country.

(3) The will of the people shall be the basis of the authority of government; this will shall be expressed in periodic and genuine elections which shall be by universal and equal suffrage and shall be held by secret vote or by equivalent free voting procedures.

Article 22: Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.

Article 23(1): Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.

(2) Everyone, without any discrimination, has the right to equal pay for equal work.

(3) Everyone who works has the right to just and favourable remuneration ensuring for himself and his family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection.

(4) Everyone has the right to form and to join trade unions for the protection of his interests.

Article 24: Everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.

Article 25(1): Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, and housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

(2) Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

Article 26(1): Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit.

(2) Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship among all nations, racial or religious groups, and shall further the activities of the United Nations for the maintenance of peace.

(3) Parents have a prior right to choose the kind of education that shall be given to their children.

Article 27(1): Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits (2) Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.

Article 28: Everyone is entitled to a social and international order in which the rights and freedoms set forth in this Declaration can be fully realized.

Article 29(1): Everyone has duties to the community in which alone the free and full development of his personality is possible.

(2) In the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society.

(3) These rights and freedoms may in no case be exercised contrary to the purposes and principles of the United Nations.

Article 30: Nothing in this Declaration may be interpreted as implying for any State, group or person any right to engage in any activity or to perform any act aimed at the destruction of any of the rights and freedoms set forth herein.

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